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EMERGING FROM THE WRECKAGE: THE EXPLORATION OF MENTAL
HEALTH, STIGMA, AND MY EXPERIENCES OF LIVING WITH OBSESSIVE-
COMPULSIVE “DISORDER”

by

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THESIS

Submitted to the Department/Faculty of Social Work
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Master of Social Work

Wilfrid Laurier University, 2014

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Abstract

This study is an autoethnography exploring my experiences of living with Obsessive Compulsive “disorder” (OCD). The stigma surrounding mental health is one of the most devastating and problematic issues in Western society today. Many individuals with a mental “disorder” suffer in silence due to the shame and fear of being ridiculed and discriminated against within their intimate and wider social networks. Obsessive-Compulsive Disorder (OCD) is currently one of the most prevalent anxiety “disorders” and is characterized by intruding obsessive thoughts and ritualized or compulsive behaviours. Individuals experience a great deal of distress and embarrassment in dealing with the stigma and misunderstanding surrounding the “disorder”. Currently, however, there is a dearth of research literature examining the subjective and intimate accounts of those struggling with mental health issues in general and OCD in particular.

In this study, I address this gap in the literature by providing deeply personal autoethnographic accounts of my own experiences of living with OCD. My data sources are current self-observations, past recollections, and a collection of personal poems, reflections, stories, and journal entries. By using an interpretive approach within the social constructionist framework, I look at both my internal subjective struggles and external societal stigmatization. Three major themes emerge from my thematic analysis of the data: guilt, shame, and hope. I discuss these findings in three chapters and provide the implications for social work in my concluding remark. In narrating my personal struggles and successes, I hope to contribute to deeper understanding of mental health and OCD, while also challenging dominant societal discourses and misrepresentations of mental “disorders”.

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Table of Contents

Abstract	i
Acknowledgements	ii
Table of Contents	iii
Chapter 1: Introduction	1
Chapter 2: Literature Review	10
A Brief History of “Insanity” and Mental “Disorder”	10
Obsessive-Compulsive Disorder	12
The Stigma Surrounding Mental “Disorder”	13
Current Research Studies	15
Limitations and Gaps in the Literature Reviewed	18
Research Questions	21
Chapter 3: Methodology	23
Epistemological Stance	23
Qualitative Methods	26
Data Analysis	32
Chapter 4: My Story, My Truth	35
The Sadness	35
Revealing My Secret	36
I Have OCD?	39
Journey of the Heart	42
The Waiting Room	47
Obsession	48
Do You Know?	50
Shifting Epistemologies	51
Shifting Identities	55
Faculty of Social Work (FSW) Equity Forum Reflections	59
2012.	59
2013.	60

Personal Journal Entries	62
November 2012.	62
July 7, 2013.....	63
July 28, 2013.....	64
September 9, 2013.	65
From the Shadows	67
Chapter 5: Guilt - The Relentless Storm Within.....	71
Dual Identities	73
Fear.....	74
Pain.....	81
Chapter 6: Shame - The Deafening External Roar	84
Fear.....	85
Hidden Identity.....	90
Disclosure and “Diagnosis”	91
Chapter 7: Hope - Taming the Storm, Dulling the Roar	98
Love and Support	102
Resilience	103
Disclosure.....	105
Gifts and Insights	107
Looking Beyond the Self: My Commitment to Others	108
Chapter 8: Looking Ahead.....	113
Appendix A.....	119
Appendix B	120
Appendix C	122
Appendix D.....	124
References.....	125

Chapter 1: Introduction

I couldn't understand

My thoughts

Making a maze in the grooves of my brain

That will never be unraveled or explained

I couldn't steady my hand

And my heart was still torn

Torn completely apart

My heart

For many years I felt isolated, confused, and battered by my anxiety and public understandings of mental “illness”. I hid deep within the shadows of stigma reluctant to expose my true identity for fear that I would be ridiculed and misunderstood. Even worse – I feared that my self-perception and identity would be torn to shreds by the claws of societal structures and the dominant discourse of what it meant to be mentally “ill”. And yet, I desperately wanted to reveal my truth to someone. Anyone. Once I was informed by a social worker that I likely had OCD, and later when I sought treatment from a psychologist and psychiatrist, I began to feel inspired by and at times angry with the social injustice of stigma. I became determined to fight the storm of judgement and inequity by screaming out to society that yes! I have a mental “disorder” but I refuse to

be beaten by it. This study uncovers my voice, my shattered heart, and the deepest agonies from within my soul because I have chosen not to allow society to dictate who I am and what I am worth.

As a means of better understanding my own experiences, I have examined the topic of mental health and “illness” and how it is perceived and addressed in society. Mental health has been globally recognized as being of significant social and public importance and the stigma to which it is attached is viewed as the most central issue in the field of mental health (Hinshaw, 2005; Johnstone, 2001). Stigmatization of mental illness is widespread in Western society and even some mental health or psychiatric professionals discriminate against their clients (Corrigan, Edwards, Green, Diwan, & Penn, 2001; Corrigan & Watson, 2002; Mann & Himelein, 2004). The public tends to negatively judge people with a mental illness more than those with a physical impairment or medical condition; as such, individuals with mental disorders are poorly treated in community (Teplan, McClelland, Abram, & Weiner, 2005). Consequently the challenges faced by individuals with a mental disorder are doubled in that they experience the painful and shameful “symptoms” and disability of the disorder while simultaneously battling the prejudice and inequity from societal forces based on misconceptions of mental illness (Corrigan & Watson, 2002).

People with mental health issues or disorders are among the most stigmatized, marginalized, and vulnerable in society (Bloch & Singh, 1997; Johnstone, 2001). The immense suffering of these individuals is arguably incomprehensible to those without mental health issues (Johnstone, 2001). Corrigan and Watson (2002) argue that stigma surrounding mental disorder can manifest itself in two forms: public and self-stigma.

Public stigma is the reaction that others have to a person with a mental illness which can cause shame and reduced confidence in one's future (Corrigan & Watson, 2002). Self-stigma is the internalization of prejudice which leads to lowered self-esteem and self-efficacy (Corrigan & Watson, 2002; Watson, Corrigan, Larson, & Sells, 2007). Corrigan, Edwards, Green, Diwan, and Penn (2001) also identify two types of public behaviours toward people with mental illness. The authoritarian attitude is based upon the belief that these individuals are unable to care for themselves and that the mental health system should make decisions for them. The second behaviour is benevolence – the view that individuals with a mental disorder are childlike and need to be watched over (Corrigan, Edwards, Green, Diwan, & Penn, 2001). Both of these societal attitudes contribute to the misconceptions of what it means to have a mental disorder while disempowering these individuals and belittling their experiences and capabilities.

This stigma can cause great distress to the individuals and their friends and family, and the consequences are dehumanizing, culturally banishing, and socially alienating (Johnstone, 2001). The suffering and experiences of living with mental health problems is a lived reality, entwined with intense loneliness and a yearning to find a way back to belonging and shared identity (Johnstone, 2001). There are many additional challenges and unfair consequences faced by people with a mental disorder. Their quality of life is often diminished through the loss of a sense of function and place in society, empathic connection to others, peace of mind, and even happiness (Johnstone, 2001). Moreover some individuals are denied secure jobs, proper housing, healthcare, and connection to social and community groups (Corrigan & Watson, 2002; Mann & Himelein, 2004). Corrigan and Watson (2002) identify further social inequities including

the withholding of mental health treatment, coercive treatment, avoidance, and the former use of segregated institutions to hold those with a mental disorder. Since the deinstitutionalization of people with mental illness there has been an increased risk of violent crime victimization of these individuals as they have been left without resources in the community (Teplan, McClelland, Abram, & Weiner, 2005). Furthermore as a result of this discrimination there have been many human rights violations within the mental health sector including the administration of medication without consent, the restraint of patients, and the denial of treatment to patients (Johnstone, 2001).

The prejudice and inequity faced by those with a mental disorder is in need of investigation and illumination as the public view of mental disorder is absorbed with stereotypes and stigma (Hinshaw, 2005). Mental health is a moral issue; thus a moral response to this unjust discrimination is required (Johnstone, 2001). This misconceived public knowledge only serves to bolster social distancing, ignorance, and punitive responses to mental health issues (Hinshaw, 2005). The understanding of the process and effects of stigma must be addressed as it has led to the limiting of research funding and access to mental health treatment (Hinshaw, 2005). Social justice for this stigmatized and vulnerable group of people can be pursued first by drawing attention to this normalized culture of unfair treatment (Johnstone, 2001). Johnstone (2001) argues that this can be achieved through the united efforts of all those involved, including individuals with mental health issues.

Individuals with a mental “disorder” often endure a “torturous and punishing” desire to be heard (Johnstone, 2001, p. 201). Corrigan and Watson (2002) argue that those who have been stigmatized either feel hopeless and their self is harmed, or they are

energized by and react to this social injustice. I have chosen, after years of torment and oppression, to break my silence and take action through the sharing of my story. This qualitative study explores how I, a person diagnosed with OCD, experience the complexities of a mental “disorder” and the stigma to which it is attached. I prefer to place the term “disorder” in quotation marks as I feel a sense of discomfort with the pathologizing and stigmatizing effect of this word. As a result of the literature review, I have identified research gaps in regards to how individuals with a mental “disorder”, and more specifically OCD, subjectively experience mental health issues and interpret various forms of stigma. Most of the research reviewed either discussed studies within a post-positivist paradigm, investigated the opinions of mental health workers (the “expert”), or utilized survey and interview methods to identify the participants’ experiences. Furthermore, there is a lack of research literature investigating the subjective experiences of mental health consumer-providers.

From an Interpretivist paradigm, this study uses an autoethnographic research design, guided by social constructionist theory and narrative theory. I have reflected upon and examined my experiences and stories of living with OCD, with a focus on significant life events. This research also explores how I have experienced mental health issues and stigma both intra-personally, interpersonally and in relation to the community while addressing the influence of internal and external factors on these experiences. Through the use of personal memory, self-observational, self-reflective, and external data, I have critically analyzed, interpreted, and reflected upon these findings within my internal and broader sociocultural contexts while investigating how socially created negative discourses about mental “illness” have impacted me. Using current mental health and

stigma literature, I have compared and contrasted my own experiences with the research findings as a means of investigating the various forms of stigma which have affected my self-perception and my beliefs about societal views and structures. Finally, I have explored how my experiences have shaped my current career and advocacy goals while theorizing how they will affect my future social work practice.

Although the effects of stigma on mental health consumers have been investigated, the voices and stories of individuals diagnosed with OCD and their subjective interpretations of their experiences are often ignored or discounted. The research that has explored the subjective experiences of mental health consumers is limited in that it often utilizes survey and interview methods (which are subject to response bias), while failing to provide an opportunity for deeper individual exploration through story-telling. I have investigated my own story of mental health as a means of raising awareness about the subjective themes and meanings of the impacts of a mental “disorder” diagnosis within my natural context. This research may allow mental health care workers, service providers, social workers, and the general public to gain a better understanding of how stigma and negative misrepresentations of the mentally “ill” affects an individual with mental health issues, and how they can be better supported within the community. Most importantly, this research will validate the experiences and emotions of others living with similar diagnoses of mental “disorder”.

The experience of mental health diagnosis can challenge one’s sense of identity, interpersonal relationships, and interpretations and meaning-making (Foster, McAllister, O’Brien, 2006). As such, individuals with a mental “disorder” continuously struggle to restore order in the face of chaos and this can be done through the method of story-telling

or re-storying the past (Block, 2008; Foster et al., 2006). Although public knowledge of physical diseases are widely understood and accepted, there is less knowledge and literacy about mental health “disorders” as it is arguably a somewhat neglected topic (Jorm, 2000). Lester & Tritter (2005) acknowledge that limitations can arise when an author of mental health research has not experienced a mental “disorder”. Using my own story of battling with a mental “disorder” diagnosis, I have been able to continue rebuilding my identity while possibly creating an opportunity for others to reinterpret their own identities and the larger construct of mental health in an alternative way.

I believe that through my autoethnographic narrative, awareness could potentially be raised regarding stigma and mental health issues. One of the most significant benefits of conducting research within the autoethnographic framework is that it will allow my experiences within and of the world to inspire the reader to think more reflectively of their own experiences. Moreover, the reader may begin to recontextualize or realign their own perspectives by recognizing and appreciating how “the other” experiences life and culture with mental health issues (Bochner & Ellis, 1996; Richards, 2008).

Autoethnography also allows the reader to engage with the evocative writing and experience the emotions of the author (Bochner & Ellis, 1996). Many people with mental health issues are denied effective and appropriate support from community members due to discrimination and a lack of understanding (Fawcett & Karban, 2005; Jorm, 2000; Ramnsay, Gerada, Mars, & Szmukler, 2001; Simmie & Nunes, 2001). Through this research, voice has been given to my own subjective experiences in sharing my story in hopes of reducing prejudice while validating the feelings of others with a mental “disorder” (Ellis, 2007; Lapan, Quartaroli and Riemer, 2012).

More specifically, within the autoethnographic methodology I have provided findings related to experiences with OCD – the internal struggle, and the external, societal forces (including stigma) in hopes of guiding future understanding and support. Moreover, I have learned that the interaction of these internal and external factors closely reflects that our emotional experiences are neither within nor outside of our being, but connect the individual with the collective (Ahmed, 2004). I have attempted to challenge the mental health consumer-provider binary through the investigation of how I have used my internal and external resources to fuel my resilience and maintain my hope of becoming a compassionate consumer *and* social worker (Carlson, Rapp, and McDiarmind, 2001; Cohen, 2010; Ungar, 2008).

Gallardo, Furman, and Kulkarni (2009) argue that a prerequisite to helping others and providing support is the understanding of one's own self. Through the examination of my own experiences with OCD and how these interact with societal structures and discourses, I believe I have become better equipped to approach the social work profession with greater empathy and understanding. If I were to ignore the deeply personal, insightful, and readily available knowledge from my own experiences, I feel that any further research or clinical work in which I engage would be lacking the fundamental and critical understanding of my own narrative. If I cannot connect with my own emotions, how can I help others connect to theirs? Furthermore, if I fail to investigate my story and challenge the dominant discourse of mental "illness" using my experiences and beliefs, how then could I advocate for others with mental health issues to do so? This research should contribute the breaking of the researcher/researched, and mental health consumer-provider binaries which serve to perpetuate the dominant power

discourses of mental health and illness (Carlson, Rapp, & McDiarmind, 2001; Poole, Jivraj, Arslanian, Bellows, Chiasson, Hakimy, Pasini, & Reid, 2012).

This study continues in chapter 2 with the review of the literature on mental health/illness, OCD, and stigma. In chapter 3 I provide an overview of the methodology used for this study, including arguments for investigating my experiences through the lens of the interpretivist paradigm with the use of an autoethnographic methodology. In chapter 4 I present my data, including all of the prose, poetry, reflections, and journal entries examined in this study. These have been presented in a loosely chronological order. Chapter 5 presents my analysis and discussion of the internal forces and processes of my experience with OCD, while chapter 6 includes my analysis/discussion of the external factors – including stigma – which have shaped my emotions and personal narratives. In chapter 7 I present my analysis of the interactions between internal and external factors while discussing how personal agency and societal structures can inspire healing and advocacy. Finally, in chapter 8 I look ahead and discuss the implications of my findings, analyses, and discussions for future social work practice and research.

Chapter 2: Literature Review

Mental health is a core component of every individual's life as it is not only related to internal states, but also to interpersonal relationships with family, significant others, work colleagues, and everyday acquaintances (Ritter & Lampkin, 2012). Mental health also influences one's contributions to the community and society (Ritter & Lampkin, 2012). Mental "disorders" are health conditions characterized by alterations in thinking, mood, behaviour, or some combination, which are associated with impaired functioning or distress (Ritter & Lampkin, 2012). Mental health issues and disorders affect 26.2% of the population or 57.7 million people in America on average, in any given year, however mental health and mental disorders are still not considered part of the mainstream health system (Jorm, 2000; Ritter & Lampkin, 2012).

A Brief History of "Insanity" and Mental "Disorder"

Foucault (1965) and Goffman (1961) depict the insane asylum from centuries past as a place of confinement and isolation for the mad and undesirable. Patients of asylums were completely separated from the outside world, further creating the divide between "normal" and "abnormal" (Goffman, 1961). From the fifteenth century onward, the image of madness as one and the same with death and ending has been ingrained in the imaginations of Western citizens (Foucault, 1965). Houses of confinement were built in the seventeenth century in Paris, to which "madmen" were rejected. Foucault (1965) argues that madmen at this time were considered monsters or beings to be shown to outsiders. Although confinement attempted to disguise unreason, it inevitably publicized madness as a scandalous spectacle (Foucault, 1965). Some insane asylums of the

eighteenth century contained “violent” madmen and women who were chained to the walls or beds with minimal clothing. The mad were separated from society as “the presence of the mad appear[ed] as an injustice; but *for others*” (Foucault, 1965, p. 228). Their presence in society was considered a burden and a danger to those that were ‘normal’ – or without any type of mental illness.

During the Moral Treatment Movement (1800-1850) asylums built in Canada were aimed at the reformation and restoration of character and behaviour of the insane (Moran & Wright, 2006; Ritter & Lampkin, 2012). Citizens were allowed at this time to tour the asylums and reported feeling “safe” when visiting them as the controlled environment and security measures kept the space from becoming threatened by the insane (Moran & Wright, 2006). It has been documented by asylum visitors that their touring was an attempt to better understand the mentally “ill”; however their eagerness to mix with the “mad” was nonexistent – thus perpetuating the boundary between “normal” and “other” (Moran & Wright, 2006, p. 40).

The Moral Hygiene Movement (1890-1920) centered on the belief that mental illness could be cured if diagnosed and treated early. Within this movement electroconvulsive therapy and the lobotomy were developed (Moran & Wright, 2006; Ritter & Lampkin, 2012). Many of the spokespersons involved in this movement were also advocates for sterilization, arguing that this method would relieve mental patients from the stress of parenting while protecting offspring from poor parenting practices (Moran & Wright, 2006).

Mental disorders are currently diagnosed by professionals based on common sets of criteria; however these criteria are rigid and provide little depth into how one experiences the disorder (Simmie & Nunes, 2001). Ritter and Lampkin (2012) argue that the threshold of mental illness diagnosis has been set by convention, based on the Diagnostic and Statistical Manual of Mental Disorders (DSM) – a standard manual for classification of mental disorders. Each list of symptoms is attached to a label which is then categorized into broader groups of mental disorders. The dominant discourse of mental illness emphasizes diagnosis in treatment in the realm of neuroscience and pharmacology while diminishing any social effects and solutions (Simmie & Nunes, 2001). In juxtaposition to this view is the argument of the antipsychiatry movement which suggests that a mental disorder is an exclusively social construct whose manifestations depend on an individual's religious, political, educational, economic, and cultural and social locations (Ritter & Lampkin, 2012; Simmie & Nunes, 2001).

Obsessive-Compulsive Disorder

One of the most commonly reported mental health problems is “anxiety disorder” which is characterized by uncontrollable and excessive rumination or worry about situations or uncertainties that interfere with daily functioning (Ritter & Lampkin, 2012; Simmie & Nunes, 2001). A type of anxiety “disorder” that affects at least 2-3% of the population is Obsessive-Compulsive Disorder (OCD) and of these, up to 66% experience comorbid depressive symptoms (Ramnsay et al., 2001; Ritter & Lampkin, 2012; Simmie & Nunes, 2001). Comorbid refers to the concurrent presence of both anxiety or OCD “symptoms” and depression (Fried, Ferrucci, Darer, Williamson, & Anderson, 2004). OCD symptoms can be divided into two main groups: obsessions and compulsions

(Ramnsay et al., 2001). Obsessions include repetitive, intrusive thoughts, ideas, impulses, or images often relating to threat of harm, violence, sex, and blasphemy (Ramnsay et al., 2001). Compulsions (or rituals) include frequent acts of checking, washing, ordering, hoarding, and counting (Ramnsay et al., 2001).

Persons with OCD tend to feel misunderstood and alienated due to the complex nature of the “disorder” and the fear of how their loved ones and the public will respond to them (Fennell & Liberato, 2007). Due to the personal shame that accompanies obsessions and compulsions and the fear of a spoiled identity, it is predicted that many people suffering with OCD keep their symptoms hidden and do not seek help; thus the prevalence of this mental health issue is likely higher than reported (Brooks, 2011; Goffman, 1963; Hyman & Pedrick, 2005; Ramnsay et al., 2001).

The Stigma Surrounding Mental “Disorder”

Stigma can be defined in a number of ways, including how it relates to individual, social, and cultural processes (Hsin Yang, Kleinman, Link, Phelan, Lee, & Good, 2007). Goffman (1963) defines stigma as “an attribute that is deeply discrediting” reducing the person “from a whole and usual person to a tainted, discounted one” (p. 3). He argues that stigma is socially constructed, embedded within a language of relationships and results from the discrepancy between how one is characterized by society (“virtual social identity”) and one’s true attributes (“actual social identity”) (Goffman, 1963, p. 2). Crocker, Major, and Steele (1998) argue that stigma is located both within the person (due to a “devaluing” attribute) and one’s social context. Stereotyping and stigmatization allows society members to dismiss and socially distance themselves from those of

difference or disability (Byrne, 2000). Although from a cross-cultural perspective stigma appears to be a universal phenomena it should not be generalized into one, over-arching experience of discrimination as it can vary in degree and quality (Hsin Yang et al., 2007).

The sociological theory of labelling posits that deviance and appropriate treatment is declared by elite groups within society based on social reactions to specific behaviour (Moran & Wright, 2006). Public stereotypes and myths of mental “disorders” are ingrained within Canadian society, and citizens often feel revulsion and sympathy towards those with a diagnosis (Moran & Wright, 2006). Negative attitudes and beliefs regarding individuals with mental health issues present themselves from early childhood and this label of “mental illness” can ignite rejection from others (Byrne, 2000; Goffman, 1963). Moreover, the public view of mental “illness” is that the stigmatized are capable of violent and dangerous behaviour due to their fundamentally “bad” character (Byrne, 2000; Wolff, Pathare, Craig, & Leff, 1996).

This narrowly-focused and misinterpreted view of individuals with mental “disorders” is further reflected in the media through news stories, television, and film (Byrne, 2000; Moran & Wright, 2006). A content analysis of American television has shown that 72% of fictional characters with a mental disorder are portrayed as violent, while studies of Canadian and British newspapers report more frequent and lengthy stories of violent individuals with a mental disorder (Simmie & Nunes, 2001). These negative images perpetuate the stereotype of the mentally “ill” while keeping societal stigma surrounding the issue intact. This stigma and community-driven fear results in the personal suppression of individuals’ mental disorder “symptoms” (Brooks, 2011; Fennell & Libearto, 2007).

Current Research Studies

There have been numerous findings in the research completed which have investigated the impacts of stigma on individuals suffering with mental health issues, and it has been reported that few human conditions have received such widespread and devastating segregation as mental illness (Simmie & Nunes, 2001). Simmie and Nunes (2001) found that the most common concern voiced by mental health service consumers was the invisible stamp of “the other”, or stigma, which is often applied to individuals with a mental disorder. Through survey results, Wahl (1999) found that individuals with a mental disorder experience stigma from numerous sources such as communities, families, churches, coworkers, and even mental health caregivers. The majority of respondents reported concealing their disorder for fear that others would treat them unfavourably, and stated they had feelings of discouragement, hurt, anger, and lowered self-esteem as a result of their past experiences with stigma (Wahl, 1999). Thornicroft, Rose, Kassman, and Sartorius (2007) found that individuals with mental health issues believe the rejecting and discriminatory behaviour of others is at times more disabling than the “disorder” itself. As a result of this unfair treatment, there is evidence that the negative effects of stigma pervade into all aspects of the lives of people with a mental health issue (Sayce, 2000).

Findings from the Canadian Mental Health Association (CMHA) of Ontario anti-stigma campaign reported that perceptions regarding people with mental disorders in the general public include beliefs that they are violent or dangerous, lack intelligence, cannot function in or contribute to society, lack willpower, and are to blame for their mental health issue (Simmie & Nunes, 2001). The findings also reported that this stigma impairs

social relationships, employment, housing, inclusion in the community, and the self-esteem of people with mental disorders (Simmie & Nunes, 2001). These findings, however, are based on the perspectives of mental health service providers, and not those of service users. Stigma limits the opportunities and interferes with full participation in society, as individuals report avoiding situations that involve risk of being stigmatized (Angermeyer, Beck, Dietrich & Holzinger, 2004; Avison, McLeod, & Pescosolido, 2007).

One of the most devastating consequences of stigma surrounding mental illness is the possibility that it will result in a significant loss of self-esteem (Link, Struening, Neese-Todd, Asmussen & Phelan, 2001). Link et al. (2001) reported that individuals with a mental health issue(s) tend to conclude that they are failures and have little of which to be proud. Simmie & Nunes (2001) reported that when an individual is repeatedly victimized by such stigma in society, they often begin to internalize the stigma, leading to feelings of being devalued and less than fully human. Fawcett and Karban (2005) reported that this stigma and label of “the other” only serves to legitimize discrimination and power imbalances that, without this form of distancing, would be considered unacceptable. Consequently, individuals diagnosed with a mental “disorder” tend to withdraw socially due to perceived rejection (Link et al., 2001). Most individuals diagnosed with a mental “disorder” describe their struggles as being associated with periods of extreme social alienation with a quality of “frozen inactivity” (Ridgway, 2001, p. 337).

This discrimination and devaluation discourages individuals diagnosed with a mental “disorder” from seeking resources and accessing treatment (Ramnsay et al.,

2001). The stigma of mental “disorder” has been blamed for low service utilization and poor individual medical and social outcomes surrounding the disorder (Avison et al., 2007). Canadian Community Health Survey (2006) reported that in a one-year period only 10% of Canadians utilized services for their mental health (Lesage, Vasiliadis, Gagné, Dudgeon, Kasman, & Hay, 2006). On a structural level, stigma is partly responsible for inadequate funding of research and treatment infrastructures, and lack of policy attention, which directly impacts service users and perpetuates social stigma (Avison et al., 2007). There is evidence that stigma may negatively influence how a psychiatric diagnosis is accepted, and whether or not treatment will be adhered to (Dinos, Stevens, Serfaty, Weich & King, 2004). Individuals with anxiety and more specifically, OCD, often remain untreated due to the suppression of symptoms, and the societal stigma that occurs when people are living with shame, guilt, and fear (Brooks, 2011).

Further research has been completed with a focus on how stigma impacts the well-being of individuals diagnosed with OCD. Fennell and Liberato (2007) found that despite being the fourth most common mental health issue in the world, OCD symptoms continue to be stigmatizing, although most individuals realize their symptoms are problematic before recognizing them as symptoms of OCD. Based on their research, Fennell and Liberato (2007) discovered that individuals with OCD come to assess what is considered “normal behaviour” through social interactions, and realize by observing others’ reactions to their behaviour, that they do not act “normally”. Brooks (2011) found that the disabling fears and rituals associated with OCD are often viewed as deviant behaviour, which leads to stigmatization in the community, causing individuals to keep OCD-related thoughts and concerns private. The fears and obsessions of individuals with

OCD include fear of killing family members, being unscrupulous, and fear of contamination, which are perceived by the individual as being publically embarrassing and morally shameful (Brooks, 2011). As a result, many more individuals with OCD symptoms suffer in silence for fear of being labelled as “crazy” (Brooks, 2011).

Limitations and Gaps in the Literature Reviewed

There are various limitations to the research reviewed. The research findings from CMHA’s anti-stigma campaign, although insightful, were drawn from the perceptions of mental health workers, and not individuals that stigmatize nor individuals diagnosed with a mental “disorder”; thus it can be argued that the results fail to include the subjective experiences of individuals that either stigmatize or are being stigmatized, which are key factors in the social phenomena of mental “disorder” and stigma. Although Wahl’s (1999) research was based on the responses from mental health consumers concerning experiences of stigma, the responses were gathered from a nationwide survey. The survey results could have been prone to response bias if the respondents answered questions in the way they believed the researcher wanted them to answer, and this would have affected the findings. Moreover, it may be exploring broader generalities rather than unique individual experiences of living with a mental “disorder”. The research by Dinos et al. (2004) was based on narrative interviews with patients from community and day mental health services. Individuals diagnosed with a mental disorder that were not utilizing these services were not included in the sample, and thus the findings do not give voice to equally enlightening subjective experiences of those outside the sample. The research of Link et al. (2001) was arguably completed within the post-positivist paradigm, as results were drawn from scale measures of self-esteem. Scale measures and

quantitative research methods limit the richness of the data by hindering participants from sharing their subjective experiences with stigma and self-esteem. In all of the research reviewed, there was a general lack of stories and experiences voiced by individuals diagnosed with a mental “disorder” using an interpretive, narrative form of inquiry.

Moreover, the research reviewed tended to emphasize the negative aspects of mental “illness” and stigma. The research of Lester and Tritter (2005) identifies a small number of service users who possessed a sense of pride for having a mental disorder. They felt it was important to own their impairment or disability, while embodying their positive experiences. Rather than feeling ashamed of their diagnosis, these individuals chose to accept and celebrate it as a central part of their identity (Lester & Tritter, 2005). This alternate, positive lens through which one can understand mental health and “disorder” deserves investigation.

There are identifiable gaps in the research in mental health and stigma. These gaps have been identified through the lens of interpretivism and narrative theory. Overall there is a lack of research focusing on the subjective stories and experiences of those with mental “disorders”, as there have been few direct contributions to the literature by mental health service users or consumer-providers (Chamberlin, 2005). The voices of those suffering from stigma are being stifled as a great deal of the research in this area has been focused on the opinions of health-care providers and the general public. Ridgway (2001) argues that first person recovery narratives can be shared to dispute this dominant discourse by allowing the audience to think beyond the deficit perspective of mental illness.

More specifically, there is very little known about how people experience OCD as there is a deficiency of research literature on the lived experiences of these individuals (Fennell & Liberato, 2007; Simonds & Elliott, 2001). There is a great need for more accessible information on the personal accounts of those living with OCD in order to alleviate isolation, misunderstanding, and hurtful social reactions (Brooks, 2011). OCD sufferers can even experience discrimination among their networks of family and friends, and this barrier could be addressed and possibly broken down through further investigation (Fennell & Liberato, 2007; Lester & Tritter, 2005). Moreover, OCD often goes untreated due to the suppression of symptoms for fear of societal stigma and unfair judgement (Brooks, 2011). Thus, as Ritter and Lampkin (2012) argue, research needs to be conducted and shared in order to educate the public about mental “illness” and reduce prejudice so that those suffering with a mental “disorder” will seek help more readily. It is critical for mental health research to “address stigma with fervor” (Link et al., 2001, p. 1625).

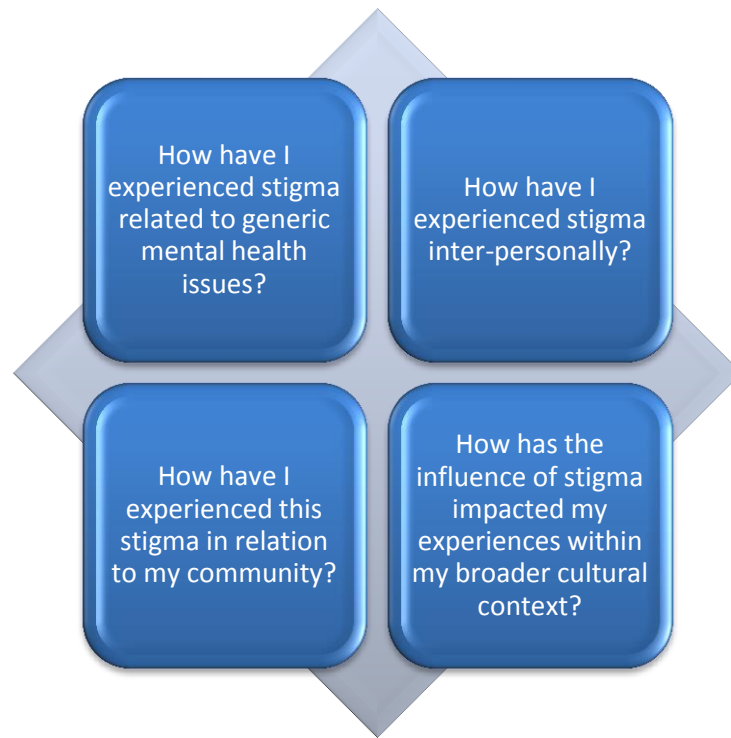
Research Questions

To explore and address the above gaps in the literature, in this autoethnographic study, I ask the overarching research question: *How do I experience OCD?* I break this into three sub-questions and ask: *How do I experience OCD internally?* *How do I experience OCD externally?* *How do I live the combined effects of both?* To engage the depth and breadth of these processes systematically, I will tease out these main research questions into further bite-size questions to guide my research process:

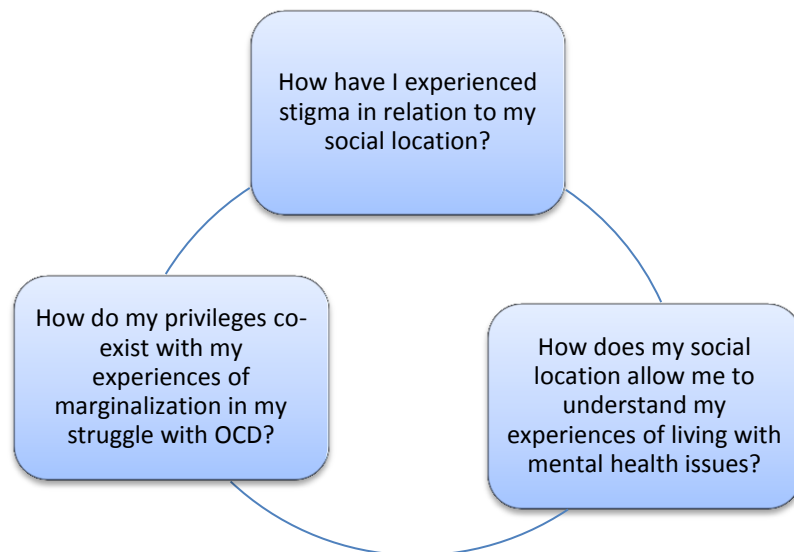
Internal Processes:



External Processes:



Internal-External Processes:



Chapter 3: Methodology

Epistemological Stance

This research has been viewed through an Interpretivist lens because I believe that the impact of mental health issues and stigma can best be investigated through the subjective experiences of individuals with mental “disorders”. I posit that reality is subjective and Interpretivism emphasizes sensitivity, respect, and appreciation for experiences of each individual’s reality (Westhues, Cadell, Karabanow, Maxwell, & Sanchez, 1999). Research within the Interpretivist paradigm attempts to remain true to the phenomenon being studied by capturing it within its natural context (Westhues et al., 1999). Within the Interpretivist framework, it is believed that there is no singular or universal truth, but numerous individual perspectives that are constructed through individual views and interpretations of reality (Westhues et al., 1999). Viewing this study through this lens has allowed the subjective interpretations of the impacts of having a mental “disorder” and the stigma attached to it to be heard and not confined by the manipulation or control of variables (Westhues et al., 1999). The individually constructed knowledge and interpretations of individuals’ experiences with mental health issues and stigma within their natural context have been silenced in research. This knowledge, however, could be vital in the process of reducing social stigma of mental “illness” and could enhance understanding of the public, and more specifically, within social work practice.

The theoretical framework for this study consists of two theories – social constructionism and narrative theory. Social constructionism holds that realities are

multiple, constructed, and a product of human activity (Pilgrim & Rogers, 1999; Robbins, Chatterjee, & Canda, 2012). Within the constructionist framework, inquiry is value-bound, and the knower and known are inseparable (Robbins et al., 2012). This approach places emphasis on the socially constructed nature of mental health and illness (Avison et al., 2007). The social constructionist paradigm assumes that people “develop their self-image and view of others through the particular context of relationships” (Coady & Lehmann, 2001, p. 376). This framework has been valuable for this study as stigma and the internalization of a negative self-image due to mental “disorder” can be better understood in the natural context of relationships within society (Simmie & Nunes, 2001). The individual definitions of mental “disorder” and stigma are shaped by cultural and social contexts and the value judgements implicit in these definitions are ingrained within the dominant discourse of mental health (Avison et al., 2007). As such, subjective realities of individuals with mental health issues should be explored to gain a clearer and more complete understanding of the effects of stigma.

Narrative theory is grounded within social constructionist thought in that it emphasizes the social construction of knowledge and the power of language to construct realities; thus it has also guided this research (Coady & Lehmann, 2008). Narrative theory and methods are often used as a framework to support a naturalistic or interpretivist qualitative method, as according to narrative theory there are no essential truths, and realities are maintained and organized through individual stories (Coady & Lehmann, 2001; Rappaport, 1995). Narrative research places the emphasis on deconstructing oppressive meanings so that new and empowering stories can be heard (Coady & Lehmann, 2001). It allows research to be conducted as though the “subjects”

are human beings with complex theories of their own regarding lived experiences (Kirkman, 2002). This was one of the purposes of this study as the effects of mental health issues and stigma can be understood more holistically through narrative inquiry. Due to the deficit of personal experiences in the stigma research literature, it is vital that stories of individuals' experiences with mental health be shared in hopes of contradicting the socially constructed, dominant and stereotypic accounts that serve to stigmatize and marginalize people diagnosed with and stigmatized by mental health issues (Saleebey, 1996). Moreover, narrative research provides the mental health field with a more insightful means to learn from consumers, which can lead to future actions of inclusion and awareness within society (Ridgway, 2001). Narrative stories can influence personal and social change while introducing new methods and ideas to those who are dedicated to the empowerment social agenda (Rappaport, 1995). The acknowledgement and public awareness of individual experiences and interpretations of stigma are essential to the process of empowering people experiencing mental health issues. As such, this research has been guided by narrative theory to emphasize the subjective experience of having a mental "disorder" and stigma within its social and cultural contexts.

This study has been guided by both theoretical frameworks because narrative theory is entrenched within social constructionist thought. The socially constructed nature of individual experiences can best be explored through narratives as they allow individual interpretations to be freely voiced. Meanings and stories are not neutral because people are born and live within a particular social context, and so I have found it essential that my research be guided by both social constructionism and narrative theory (Saleebey, 1995).

Qualitative Methods

Qualitative research is appropriate for investigating and understanding the meanings individuals or groups attribute to a social or human problem (Creswell, 2009). Qualitative inquiry utilizes an inductive style, building from particulars to general themes while making interpretations of the meaning of the data (Creswell, 2009). There is a focus on individual meanings while appreciating the complexity of situations, which allows the structure of the study to remain flexible (Creswell, 2009). The qualitative research method was appropriate for this study as I have investigated the subjective, individual story of how I have experienced OCD and stigma, which could most richly be explored using an inductive, interpretivist form of inquiry. The flexible structure of the qualitative method has allowed themes to emerge from the data which have provided an opportunity for my subjective experiences and insight to be voiced and shared.

The qualitative research strategy that I have used for this study is Narrative Inquiry. Narrative research as a method begins with the experiences as expressed in lived and told stories of individuals (Creswell, 2013). The research process involves studying an individual by gathering data through the collection of one's stories, reporting individual experiences, and chronologically ordering the meaning of these experiences (Creswell, 2013). This research design has been chosen because these stories and experiences have provided rich and insightful data. Conventional positivist research may provide meaningful findings, however "human actions are most complexly accounted for through narratives" (Lapan, Quartaroli and Riemer, 2012). This method also preserves the integrity of individual events and interpretations that cannot adequately be understood in terms of variables or discrete elements (Reissman, 2002).

More specifically, I have used an autoethnographic methodology for this study because it cannot be disputed that culture and individuals are intricately intertwined (Chang, 2008). The rationale for this design has been based on important factors. Firstly, it has allowed many elements to be explored including multiple layers of consciousness, the vulnerable self, the coherent self, critiquing oneself in social contexts, the disruption of dominant discourses, and the evocative potential of the research (Muncey, 2010). These are all important facets to be investigated in order to understand the impacts of experiencing and being diagnosed with a mental “disorder” within the greater, cultural and social context. Autoethnography makes visible the connection between individual experiences and the broader societal culture; as such this methodology has allowed for a richer investigation of the social phenomena of stigma (Muncey, 2010; Chang, 2008). Additionally, autoethnographies have the potential to reduce prejudice, raise consciousness, and give stigmatized and marginalized people a voice (Lapan et al., 2012). It also helps to alleviate and validate the author’s pain, while simultaneously allowing the audience to feel validated (Ellis, 2007; Lapan et al., 2012). Thus, the purpose of this study could be most adequately accomplished through an autoethnographic methodology as it has allowed for consciousness to be raised about the issue while validating the pain of others dealing with the effects of a mental “disorder” diagnosis – that is the guilt, shame, and societal stigma. Moreover, autoethnography is a researcher-friendly methodology in that the researcher is privileged with a holistic and intimate perspective of their data to which they have full access (Chang, 2008). This design is also reader-friendly due to its personally engaging writing style, which can raise awareness of the subject in the general public, as well as in the professional and academic field of mental

health (Chang, 2008). This has been an essential component for this study because my personal experiences with mental “illness” and stigma, and other similar narratives, should be brought to the attention of the greater public and the professional mental health field.

For the purposes of this study, it has been important that I remained reflexive of my own biases and beliefs throughout the research process. The subjectivity of the autoethnographic approach has the advantage of being rich and intimate however it does not come without disadvantages. Due to the methodological focus on self, my own biases are inherently present in the research and it has been vital that I remain cognizant of these biases while interpreting and analyzing the data. There was the possibility of an overemphasis on the narrative aspect of the study, but the ethnographic piece of the research, including cultural interpretation, could not be ignored. The use of personal memory and recalling as a data source has allowed some data to be filtered through the lens of my arguably privileged social location and biases; however it has been important that I explore my experiences with mental health issues as they relate to my position of privilege. Although I have suffered and continue to live with the diagnosis of mental “disorder”, I have been privileged in terms of socioeconomic status, race, sexual identity, familial structure, and education, and I have never been hospitalized for my “disorder”. As such, my experiences and interpretations reflect these advantages and the lens through which I made interpretations of the data.

Furthermore, because I have experienced specific symptoms of OCD, I may have brought forward my own assumptions regarding how guilt, shame, and hope affect people with OCD; however, my experiences may differ drastically from another individual’s

depending on their symptoms and social location. The evocative and emotional nature of this methodology has the advantage of providing insightful data that has the ability to touch the lives of others. I attempted to remain aware of my position as a social work student as this likely influenced my interpretations of people whom I believe have discriminated against or oppressed me throughout my life. Through reflexive critique of my own thoughts and emotions throughout the research, I have remained cognizant of these biases and my social location.

Autoethnography positions the researcher as the subject of the study. I am the only subject in my study as I provided all of the primary data. I interpreted, critically analyzed, and reflected upon the data within my broader, sociocultural context. The generalizeability of the study may be called into question because the data is generated by a single subject and may not be able to illuminate all general, cultural processes (Ellis & Bochner, 2000). Additionally, the reliability of the research, defined by the credibility of the author, may be called into question due to the intimate and personal characteristics of the data (Lapan et al., 2012). There are strengths, however, to this study that outweigh the aforementioned limitations. The chosen sampling strategy has allowed the data to be highly subjective and, because the researcher is also the subject, the findings will illuminate previously hidden personal experiences of mental health issues. Using an alternative methodological approach would have resulted in less rich and evocative accounts of my subjective truths surrounding the issue, only serving to perpetuate the silencing of marginalized voices. Autoethnographic data will disrupt the dominant discourses surrounding individuals diagnosed with a mental “disorder”.

I have collected three types of primary data: personal memory data, self-observational and self-reflective data, and external data (Chang, 2008), which are all related to my experiences with OCD. Personal memory data was used as a primary source of information in the research and was collected and written as textual data recalling my past. I chronicled significant past experiences by describing events or experiences from my life that are related to OCD (Chang, 2008). I have also taken an Inventory of Self by collecting, evaluating, and organizing bits of memory that relate to my experiences with OCD, which I have documented as textual data (Chang, 2008). There are some limitations to personal memory data as memory selects, shapes, limits, and distorts the past (Chang, 2008). Reconstructing details from the past is challenging work; however it is within these memories that the subjective experiences and alternate discourses have been found (Chang, 2008).

Self-observational and self-reflective data have been collected throughout the research process. Self-observational data has allowed me to capture my thoughts, behaviours, emotions, and interactions as they occurred in the present (Chang, 2008). I recorded systematic self-observation using a flexible, narrative format which has allowed me to describe in detail my observations and interactions (Chang, 2008). This was done “on-site” (immediately) during the research process. A limitation of this data collection procedure is that thoughts were occasionally disrupted, and my self-awareness could have changed the natural rhythm of daily activity (Chang, 2008). Self-reflective data has been the result of introspection, self-analysis, and self-evaluation (Chang, 2008). This data was recorded using a field journal, where I recorded my private thoughts and emotions

regarding the research process. Through self-analysis I was able to remain reflective of my personal values, which are shaped by cultural standards (Chang, 2008).

Finally, I have collected external data in the form of textual artifacts. I have used personally produced texts in the form of essays, poems, and journal entries I have written in the past and throughout the research process. These are essential sources of information as they “preserve thoughts, emotions, and perspectives at the time of recording, and remain untainted by the present research agenda” (Chang, 2008, p. 107). I have also used my own entries in Hyman and Pedrick’s (2005) *The OCD Workbook: Your Guide to Breaking Free from Obsessive-Compulsive Disorder*. One of the strengths of this data collection procedure is that it is subjective and accurately reflects my own perspective and interpretations of the research topic.

I have recorded my data in word documents. The collected data has been labelled, classified, and refined throughout the research process (Chang, 2008). Primary, organizational labels with the time/date, recorder/collector, collection technique, and data source have provided initial information regarding the data (Chang, 2008). The secondary, topical label has been used to describe contextual information or content of the data, including main actors in the data, the timeframe of the data, and geographical information on the data (Chang, 2008). These procedures have been tracked in a Data Log (see Appendix A). The labeled data sets were then classified and coded into groups for later analysis (Chang, 2008). The procedure of data refinement has been used to eliminate any redundant data from the data sets as means of focusing the research (Chang, 2008). Field journal entries have first been handwritten, subsequently recorded in a word document, and labelled appropriately for later analysis. Handwritten field notes

may have been less detailed due to the time consuming nature of the procedure, and consequently they may have been less thorough than typed notes; however it has been more convenient and practical to record handwritten notes on-site.

Data Analysis

Data analysis has been interpretive and based on Chang's (2008) suggested data analysis strategies for autoethnographic research. The analysis and interpretations have explained how my life experiences are personally and culturally meaningful, and have also explored how my internal experiences have interacted with these external, societal factors (Ahmed, 2004; Chang, 2008; Rose, 1996). I began by searching for recurring topics or themes within the collected data, and categorized the data accordingly. I have also analyzed the relationships (according to my own stories and current literature) between self and societal structures (Chang, 2008). Finally, I have looked for cultural themes within the data that describe relationships among various elements in my social context and how these relate to and interact with my internal experiences (Chang, 2008). I have weaved together the analyses and discussion of my findings by including literature and published research findings and comparing them to my own data and experiences. In doing so I have been able to critically discuss how the literature and my own findings relate to one another.

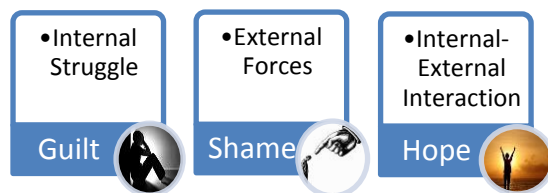
To ensure the quality of my study, I have focused on trustworthiness, authenticity, creativity, and expressiveness (Patton, 2002). The stories and analyses have been embedded in my lived experiences, have a distinct and expressive voice, and are interpretive and stimulating in hopes of connecting with the audience. I have remained

creative in the writing and interpretation as a means of opening the hidden aspects of my lived experiences to the audience. I have ensured dependability by remaining reflexive and cognizant of my thoughts, feelings, and behaviours throughout the research process while staying true to the chosen interpretivist paradigm. Furthermore, I have attempted to be conscious of my own beliefs, biases, and social location when interpreting the data while reflecting on the impacts these biases could have on the research findings. I have also remained aware of establishing validity and credibility in the study by ensuring the findings are lifelike, believable, and coherent to important stakeholders (Lapan et al., 2012). To ensure confirmability, I have made certain that the findings are related to the data collected so that the reader will be able to follow the logic from the data to the final report (Patton, 2002). In the analysis and discussion chapters I have included italicized fragments – either as direct quotations from the data sets or as reflexive narration which represents the cognitive and emotional processes from the data. This has created cohesion between the data sets and the more intricate analyses. I have made regular, reflexive field journal entries to ensure transferability by providing context for the data. Finally, I have attempted to ensure authenticity by remaining critical of my own experiences and interpretations within my social context, while simultaneously providing evocative and intimate stories of these experiences.

The thematic analysis of the data sets has been a thorough and carefully approached process. I began by identifying recurring and significant emotional themes within each piece of data. Initially I discovered five major themes: pain, guilt, shame, fear, and hope. I colour-coded the data according to these themes by picking out words, fragments, and sentences that appropriately reflected each theme. Upon reviewing the

findings based on these themes, it became clear that my emotional and cultural experiences could be further teased out into more vast, overarching themes and specific and precise subthemes.

I discovered that my experiences could be described under the following major themes: internal struggle, external forces, and the interaction of internal and external factors. I examined my feelings of guilt and realized that although they could have been fueled by external, societal factors, guilt has in my own life been an internal battle. Within my guilt, three subthemes manifested themselves in the data: dual identities (impure/evil versus good), fear (of my own mind), and pain. Within the external forces which have affected my experiences with a mental “disorder” and societal stigma was the theme of shame. Within this theme, I examined the subthemes which presented themselves in the data: fear (of judgement from others), my hidden identity, and disclosure and “diagnosis”. Finally, I synthesized the two major themes of internal and external factors to analyze and discuss how they have interacted with one another to create hope. Within the theme of hope I have found the subthemes of love and support, resilience, disclosure, gifts and insights, and looking beyond the self: my commitment to others. I discuss how personal agency and societal structures have been related to one another in my own narrative, and how I have used internal and external resources to combat stigma and discrimination by creating a hopeful future for myself and others.



Chapter 4: My Story, My Truth

This chapter includes a loosely chronological presentation of my experiences of living with OCD. I have woven together poetry, reflections, stories, and journal entries that I have written throughout my life as a means of expressing my uncensored and deepest emotional processes – both internal and in relation to my cultural and community contexts. This is my raw data, my story, my reality, and my truth. I have decided to include my narrative in this form prior to analysis and discussion as a means of providing a prelude or foundation from which my analyses are drawn (Ellis, 2002; Neville-Jan, 2003; Smagorinsky, 2011). This may allow the reader to become better oriented to and immersed within my experiences, which in turn will give the analysis more evocative meaning.

The Sadness

I throw back my head,

Let the sadness drain away.

But it drips into my heart,

And leads me astray.

The sadness stings and rushes to my face.

A teardrop comes and goes,

As if a loved one's in its place.

Life seems like a puddle;

An object I can see.

When times like these find my path

I am floating in a sea.

I lift my head and gaze

Into my cloudy, hopeless plight.

God knows what is to happen,

And what is to happen will be right.

This poem was written during my early adolescent years. At the time I did not know why I had such sadness in my heart. I was unaware of the “symptoms” of OCD and simply believed I was going through natural emotional phases that are inevitable for anyone my age. This writing reflects the deep turmoil that stirred within me for so many years, and expresses the depressive state that frequently dragged along behind my bouts of severe anxiety. The depression always lifted after some time, but it never fully disappeared. It always returned along with the obsessions that plagued my mind every day.

Revealing My Secret

I was around 17 when I first told someone about my experiences with OCD. The first person I ever told was my mother. Unfortunately, at that time I did not know I had symptoms of OCD or anxiety. Growing up all I had ever learned about OCD (which was nothing substantial) was that people with the diagnosis washed their hands excessively,

were afraid of germs, and counted their steps. Consequently, because my experiences did not fit into that box of specific symptoms, I did not consider the idea that I too could have OCD.

I was doing homework at home one afternoon. I was home alone and had been suffering with intrusive thoughts for about 3 years already. As I was attempting to do my work, thoughts of suicide kept jumping into my consciousness. Thoughts of violently ending my life, and sudden feelings and urges to hurt myself continuously tugged at my mind. I was so confused. I had a great life and everything was in place. I loved my family and my friends, and on the surface I was doing well in every domain of my life. Why would a person who had it “all together” want to end their life? I knew why. I was not happy, nor did I have anything together. I was falling apart from the inside out, but no one knew except for me.

Finally the tugging thoughts turned into merciless punches. The tears poured down my face and the sobs tore at my throat as they tried to escape. With nowhere to turn I retreated to the bathroom where I laid on the floor, suffocated by the anguish and confusion in my mind. I don’t know if the thoughts and feelings were true, or if the suicidal ideations were intrusive thoughts; regardless, the pain was real. After ten years of trapping my horrid thoughts, urges, and images in the depths of my being and suppressing the doubt and guilt I felt as a consequence, I was finally coming undone. Ten years of brokenness, and now I was shattering.

I heard the door slam, and I knew my mom was home from work. As had become custom through the course of my life, I made myself stand up and wash my face with

cold water to hide any evidence of tears. For some reason though, I knew that today had to be different. Instead of pretending I was busy I sat in the bathroom alone and waited. When my mom came in to say hello she knew something was not right. When she asked what was wrong the tears came flooding back and I revealed the twisted, dark, and mangled part of myself that had been consuming my life.

I began by saying, “I did something bad.” That was an understatement. Especially in the last 3 years, I had been convinced by the guilt rotting my soul that I was truly evil. What kind of person has such violent thoughts and images racing through their mind? If I were the good-natured person everyone believed me to be, they surely would change their opinion once they knew that I had recurring and intrusive thoughts of hurting my family members. With some hesitation I continued: “I think about killing you.” Saying those words aloud for the first time was like being stabbed with a knife in the stomach. At that moment, I think I would have rather been stabbed than reveal such a shameful secret to one of the people I love most in this world. I revealed that I have had horrible thoughts for the past few years, and that before then I felt the need to tap, count, touch, or look at things in a certain way while thinking the “right” thought. I felt a strange sense that I would be “cursed” if I did not do things the “right” way. It was too difficult to understand and so I convinced myself I was insane.

I expected my mom to look back at me in confusion, disbelief, and disgust. Along with the violent and gruesome thoughts that consumed me every day was the image of me in a straightjacket, locked in a room in the psych ward. I always pictured my family peering at me with sadness and disappointment through the tiny window in the door of my hospital room. I dreamt of and dreaded the day that I would tell my parents the truth

about the workings of my mind for the past decade. However, being the gracious, empathic, and loving woman she is, my mom smiled at me and told me it was okay. I hugged her with all of the strength I had left and buried my head into her shoulder to weep. Instead of the nightmare that I feared for most of my life, she made one of my most distant dreams come true. She suggested I see a professional about the worry and pain I was experiencing. I agreed with relief, and yet I still had some trepidation about what the counsellor would think of me. Perhaps an objective outsider would be less understanding.

I pushed that worry to the back of my mind that day and focused on the courageous risk I had just taken. I had conquered what remains one of the most difficult feats of my life. For so many years I had been determined to reveal my truth to someone, but shame and fear prevented me from doing so. This was a day I would never forget, and although it was followed by intense struggle and anxiety, it was the beginning of my journey toward healing and facing the stigma that held me captive for so long.

I Have OCD?

I sat in the waiting room of the counselling office, looking nervously at the bulletin boards full of mental health awareness posters. I remember seeing the one poster at my doctor's office for a few years. It always filled me with dread and fear. It said something like, "You go to the gym to take care of your body, so why not take care of your mind?" Well...when they put it that way...it didn't sound *so* terrible. But it was. That poster was there to taunt me, to make me feel guilty about hiding my insanity, and now posters just like it were staring me in the face from all directions.

But this time was different. This time I was here seeking help from a social worker, on my own accord. I was no longer hiding my problems. I had spilled my guts, so to speak, to my mom months ago and now I was finally going to talk to a professional about the thoughts and behaviours that were driving me down a spiral of anguish for so long. Although this may seem like a daunting and terrifying event, for me it was somewhat of a relief. I had dreamt for years of “confessing” my strange actions and thoughts to a counsellor or psychiatrist, to be reassured that I was “normal” and that yes, I could now stop worrying.

My mom had spoken to the counsellor earlier and told her what she knew of my difficulties. The counsellor suspected I had a “chemical imbalance”. That was music to my ears! Knowing there was a scientific explanation for my twisted, abstract, and disturbing thoughts made me feel so incredibly relieved. In our appointment, she stated that she believed I had OCD. Although the counsellor was unable to formally diagnose my issues, all I knew was that it seemed to make sense. The puzzle was finally being put together. I later received care from a psychologist and psychiatrist for my issues and intruding obsessions and compulsive processes.

After I met with the social worker, I was immediately referred to my family physician to look into medication options for my anxiety issues. I was filled with a new sense of joy and hope for my future as I believed these little pink pills would begin to solve my “imbalance”. I think I would have literally ingested anything that was given to me with the promise of reduced anxiety. I had no idea that my nightmare was only beginning to stir.

As soon as I started taking the medication my symptoms seemed to multiply exponentially. One of the first days I started taking my pills I experienced terrifying auditory hallucinations. I was in my home alone when I suddenly heard a blood-curdling scream of a man in severe pain. I somehow knew it was not a real scream, but that only made it all the more horrifying. I was actually losing my mind. I walked upstairs and went into the washroom to try to calm my nerves when suddenly the room crept in on me. The walls blurred and melted toward me, my chest tightened and my body went numb. I stumbled to the ground as my legs could not hold me, and my vision was flooded with fuzzy darkness. I will never forget that experience as it was too intensely confusing and agonizing to fade from my consciousness.

For the next few months I struggled with less intense but more frequent and abstract psychosis. The workings of my mind during those dark days are still too intricate and horrendous to describe in words. It was as though I was living in a dream-like state but I was afraid to close my eyes. Even sleep was no escape from my painful (and alternate) reality as my obsessions and hallucinations would follow me into my dream-world. Some nights I would not sleep as I was too afraid of where my distorted mind would lead me next. Other nights I slept with the television on to distract my brain, but even then my mind found a way to twist the words being spoken or the music being played in a way that I could never understand.

These were the shadowy days in which I lived following my “diagnosis” of OCD. Although my mental health improved as time went on, those days will haunt me forever. The battle was not won; the war in my mind and in my heart continued to rage.

Journey of the Heart



Take Hold of a Bleeding Heart (n.d.)

I wasn't ready

Unstable, unsteady

My thundering heart soared to my ravaging throat

It shred my heart apart with its blade of unfairness

My heart it shred

And it bled

Oozing and scorching with the fear it held

My mind was throbbing, my head was throbbing

My soul bobbing up and down

High to the glorious, eternal sky

Then splat!

Flattened and crumbling to the ground

I couldn't understand

My thoughts

Making a maze in the grooves of my brain

That will never be unraveled or explained

I couldn't steady my hand

And my heart was still torn

Torn completely apart

My heart

I lost all I ever felt

So on my bruised and slashed knees I knelt

And screamed in pain as the blood was drained

Making rivers in the ground

I was pleading for peace

For the tearing, the ripping, gripping demon to let go

To cage another victim

In the steel bars of living death

Where the beast awaits the mind's impure flesh

Forget my life and all it holds

All I ever held in the palm of my mud-drenched hands

I had to wash them clean

And down the drain with happiness it all went

With my sparkling, silver dreams

With the remnants of my bleeding heart

That was torn apart

My heart

Then I was alone

With the terrifying screams

The shrill phantom voices echoing

Escaping my tangled brain

I did not cry

The steaming rain

Did not fall that day

I was a slave, impoverished without love

Working for the terror aching inside

Cracking open

Exposing where the paranoia had to hide

I couldn't move

Didn't remember what was real

It was hell

The flames of injustice

Set my soul on fire

Shrivelling it up in the skeleton I became

I broke down, grabbing all I could find

And for now

For now all I want

Is to retrieve a renewed mind

And I hope

My heart

Will be sown back together

With stitches of forgiveness

By the gracious hands of God

And the angels descending

Like snow dancing above the ground

I pray my demons will depart

From my burning, aching heart

Let it glow and shine forever

In the eternal skies of peace

Put it back together

Let it finally be free

My heart

Let it finally be free

Free from the terror that will forever

Hold me

This poem was written following my “diagnosis”. I wrote it in my final year of high school (2006) as part of a poetry assignment. Although I had written poetry in the past when I was suffering emotionally, it was the first piece I wrote that specifically reflected my painful experiences with OCD. More importantly it was the first time I was allowing my vulnerability and anguish to be shared with other people; however the source of my pain was not disclosed. I cherish this piece of writing because it digs so deeply and passionately into the raw torment I was living through at that time. I consider it an extremely accurate account of my anguish for it was written in the midst of my battle with OCD.

The Waiting Room

My heart pounds as my palms become sticky with sweat. I bounce my legs up and down with the wiggling of my restless feet. I can feel my face flush with heat - heat from the burning in my heart, the terror in my soul. Today I see my counsellor. I have been to counselling before, quite a few times actually. Every session is the same. I wait. I await my fate – my doom. I have to tell. I *have* to tell of my newest obsession, of the thing from my past that is nagging at my brain, screaming that I am crazy. I have to get approval, reassurance that I am not evil. “It’s just the OCD”. Oh please, let it just be the OCD.

What if I forget a very important detail? I cannot! I have to remember every detail or else the story will be incomplete, and how can they tell me it’s just the OCD if I forget that one detail that demands there is something wrong with me. I’ll have to book another appointment - for tomorrow.

My heart pounds harder, faster. I wish it would leap through my chest so I can stop feeling such agony. This might be it for me. Today might be the day that they tell me there is truly something wrong.....Oh please - don't let me be a bad person. Oh please....

...."Katelyn? Hi."

This is a representation of what I experienced each time I sat in a waiting room before a counselling appointment. Although the counselling was meant to ease my anxiety and renew my strength to cope with the obsessions, I often felt my anxiety increase before each session. Even to this day I cling to the fear that I am the violent, evil, and insane criminal that I see in the media. I still wait for the day that they "take me away" like a mad woman to the asylum of centuries past.

Obsession

Panic flooding over me, chest tightening, heart racing, stomach lurching, legs going numb, tears welling. I've had a thought. A bad thought. A realization that I am truly a terrible person. It hit me so hard, like I ran full speed into a brick wall. It hurts so badly.

HOW could you do that!? How could you think that way!?

What is WRONG with you?

There is something seriously wrong with you. This time it is certain. There is absolutely NO doubt now that you are not good. You are fundamentally bad. BAD. Why are you even alive?

You are a terrible person.

A terrible person.

A terrible person.

A terrible person.

Cry because there is nothing else left to do. Surrender your logic and rationale because it is useless here. No matter how you look at the situation, you cannot escape the fact that you are awful. If your family and friends knew about this, they would be in shock. They would not love you at all. They would not want to be around you and you would be alone. Forever. Alone. You would lose all that is important to you because you are NOT A GOOD PERSON!

Tell someone.

You have to tell someone.

If they don't know this ONE thing, then how can they measure your entire worth?

There cannot be one piece missing from the puzzle that is you.

You can be 99% good but that 1% will make the rest of you worthless. You are worthless. People like you don't deserve to be happy.

If you tell someone you'll feel better because you won't be a lie. You can't hide the bad parts of you because that is a lie. You will always be a lie because there are too many bad things that you've thought or felt. Too many to keep track of. Too many to tell people.

Therefore, you will always be a lie. A bad, lying, worthless person. That is you.

Now cry because you have nothing left to do.

This free-association poem reflects the process of self-talk that I endure each time I am struck by a new obsession. This represents how I convince myself nearly every day that I am not a person of worth, and how the shame and guilt surrounding the obsession pushes me down until I am too weak to get up again. Although I have attempted many times to reverse this negative self-talk, I am usually unsuccessful at overcoming and working through the guilt and dread that brews within me. Despite their best efforts, I feel it is difficult for others without OCD to truly understand how it feels to be bound to the obsessions flooding my mind. I have reflected on this in a poem:

Do You Know?

Do you know what it feels like to be afraid of yourself

To be truly living in fear

With no sight of escape

Do you know how hard it is to hate yourself

To think you have no control

To fear that your mind is quickly slipping from your grasp

The panic surrounding your uncertainty

To feel you're not even safe with yourself

To fear the sharp edge of the razor

That wants you to bleed

I do

This is the torture, the torment

That kept me bound to secrecy

My soul shaken

Crumbling

Bleeding

Do you know what it feels like to be trapped

A sea of anguish

Washing over you every second, every breath

I do

Shifting Epistemologies

The following piece is a reflection written in my first year of study (2012) in the Master of Social Work program at Wilfrid Laurier University. Within this piece I investigated my own biases and perspectives of mental “illness” and how these shifted drastically upon beginning the program. I used my own experiences with OCD to better understand how I hope to interact and work with others facing mental health challenges.

Everything I once stood for has changed. When I came into the MSW program, I had a clear path of focus. I was going to change my community, one “broken” client at a time. Some may have commended me on my determination, my vision, while others

would call this naivety. Before I began this program, I felt strongly about my beliefs, but now I see my former self as a Psychology Major with tunnel – vision. I came from a field of hard science. Mental illness was viewed as just that – a set of illnesses. From my previous training, I assumed that assessment led to diagnosis, which then led to a cookie-cutter intervention, depending on the disorder at hand. Although I recognized the vast issues related to stigma and marginalization of those with a mental illness, I was unaware that I too was a perpetrator. By labelling my future clients as “ill” and in need of particular interventions, I was quite frankly missing the mark.

I am now going to be more honest than I have ever been in an academic setting. I have, for many years, suffered silently under the stigma and label of having a mental illness. From my own battle with oppression has emerged my undying passion to promote awareness in communities of what it means to be mentally ill. In the past, I often compared my mental illness to diabetes when trying to explain it to friends and family. Just as a person with diabetes would need insulin, my brain did not produce enough serotonin, and thus I needed medication to make me “better”. It made me feel relieved to attach a name and a quick-fix to my personal struggles. I was simply a sick person in need of medicine. I always wondered, however, how a simple label could explain my nearly twenty years of personal triumph and defeat. How could a label tell people about the countless nights I spent lying awake in bed, the days I spent crying because I did not understand, and the happiness I felt when I could rationalize my “inappropriate” thoughts? By giving myself a label, I was giving others permission to stigmatize me, to push me into the margins of society, and to assume they knew who I was without ever

knowing me at all. *I* was pushing myself into the flame of oppression, all the while thinking I could extinguish the fire by promoting awareness. How uninformed was I!?

One of the first things I learned when beginning this program was that as a social worker, one cannot attempt to push a client into a theory. It is not helpful to simply assign a theory (cause, effect, and intervention) to a person without paying any mind to their individual situation. Every person comes with their own context in which they exist, and it is unfair to dismiss any information that does not fit into the theory in mind. One thing I always repeated to myself when I was feeling discouraged with my mental illness was the mantra that my illness did not entirely define me. I could recognize and understand this concept for myself, but when it came to academia, I often attempted to push people into theoretical boxes, labelled and all. Now, I am throwing those boxes in the trash and looking at the *person*, not the problem. I certainly do not want to have assumptions made about me based on my label. The general view of mental illness as only being a deficiency and a problem to be fixed can cause great distress. The despair felt by those with a mental illness is in part a result of the stigma attached to it, the dominant view that having a disorder is unfavourable, and that dreaded box labelled “ill”.

My own anguish has been a result of fear. As a child, I could not disclose my experiences to anyone for fear that I would be treated differently. I did not want to be seen as less of a person, nor did I want to be locked up in the hospital because I was “insane”. I knew in my heart that I was still the loving, caring person I was brought up to be, but would society still see those traits if they knew I was ill? Or would their perspectives be clouded by my big, bold label of “CRAZY”? The next time you hear the word “crazy”, try imagining a young child battling the faceless demons of mental illness

without any support. It was not the disappearance of fear that brought me to my knees, to surrender and tell my story. It was simply my inability to cope any longer on my own.

Ten years of hiding, and finally I was free. However, I was not free. I am still not free. I am constantly being weighed down by stigma, and I will never be free until this stigma is lifted. It may take longer than my lifetime for the common perspective of mental illness to be shifted. My hope is that communities will stop putting the emphasis on deficiencies and problems to be cured. Why not look at the flipside of this?

I believe the complexities of the person interact with the “illness” to create something truly unique, and arguably beneficial, both to that person and to the community as a whole. When I ponder what my life would be like without my mental illness, I have a hard time finding in it any meaning or purpose. Although my illness does not define me as a whole, it does weave its way into different aspects of my being, and not necessarily in negative ways. I would not be the same driven student with a strong work ethic, nor would I have such a keen sense of observation. I may not be as compassionate or empathetic as I am now, and quite possibly I would not be in the MSW program. From this perspective, I see more deficiencies when I *take away* my illness. If this is so, then why call it an illness at all? My new focus is not one of inadequacies to be mended, but one of assets to be celebrated. Each individual is unique and gifted in his/her own way, with or without mental health issues. By focusing on the positive aspects of one’s identity as a result of mental health issues, I aspire to instill within my future clients a sense of pride and resilience. Although surprising to some, I would never trade my painful experiences for anything. My hope is that others who are suffering will someday feel the same. If others in our communities could shift their focus from one of faults to

one of giftedness, we may well see stigma fade. I will be in the middle of the road, gladly waving goodbye.

Shifting Identities

The following piece is another reflection written during the MSW program (2012). It explores my struggle with understanding my different identities and how being in the program has allowed me to examine them more closely within a new social context.

Who am I? Such a clichéd question that we have all pondered at one time or another. I ask myself this question daily because I am constantly struggling with my identity within social contexts. When I was a child I battled alone with this dilemma, but my scope was narrow and unforgiving, driven by the stigma of mental illness. I was engulfed by this stigma created by society and let it control my innermost thoughts and perceptions of myself. As I have grown into adulthood I have realized that my identity is shaped by so many differing factors, and this only serves to complicate the matter further. Being a social work student has also caused me to be more critical and reflective of the values and ideas that shape my perception of self. I hope that I can one day pinpoint my multifaceted identity with confidence, but that remains to be seen.

Growing up I felt I was leading a double life. To others I was an energetic, lovable child with the world at her feet. I was a master at making it appear that I had everything in order and would inevitably be a success in one way or another. I was quite aware that the people around me would never suspect, just by looking at my life, that I was suffering. On the inside, however, I was falling apart. The inexplicable behaviours I

felt compelled to perform, coupled with the horrific thoughts and images constantly racing through my mind, led me to believe I was one of two things: I was going through a phase that was perfectly normal for children my age, or I was completely insane. Societal messages brought to me through popular media and adult conversations truly influenced the way I perceived myself. The stigma in my community attached to people with mental illness caused me to live in genuine fear of my own mind. I was often convinced that I was insane, but the other, “good” half of my identity was constantly playing tug-of-war with this idea.

As a child without exposure to any level of education or awareness of mental illness, I truly internalized the label of “crazy”. My society failed to provide any information or attainable resources for children with mental illness. Without even having the chance to understand my own situation I was forced to agree with what society was telling me. I used to look in the mirror and barely recognize myself. I did not understand who this person was staring back at me, or why she was thinking such disturbing thoughts. I would say to myself silently, “If you don’t stop doing this they will take you to an asylum and lock you up.” My mind was flooded with visions of white rooms with small windows in the doors, and my family staring solemnly in at me as if I were an animal at the zoo. The most despairing detail was that I truly believed this would happen to me one day. I desperately wanted to just be the girl that everyone else saw, free of shame, confusion, and the dread of being punished for my “insane” tendencies. And so, I hid my “second identity” from the community and made it my mission to discipline myself to the point of being cured. Stigma overtook my life and forced me to suppress my whole, multifaceted identity.

When I grew older and finally (at the age of eighteen!) learned some truths about mental illness, I had a fleeting sense of relief and liberation. For the first time I could say with confidence that I was not in fact, insane. According to my therapist, I was suffering with a mental illness and that was okay. I believed that my distress would abruptly come to an end with this revelation, and that my symptoms would disappear. I thought the stigma that had followed me around like an unwanted shadow would fade from view, but I was wrong. Although my self-perception was less foggy, this new label that was attached to me by my community would affect my life in a different way, and I would now have to untangle all the new strands attached to my identity. The wave of new information I was receiving about mental illness was overwhelming, and it completely shook up my concept of self. I felt compelled to share this new, medically-laden label with those around me, even though I did not truly understand what it meant.

The next few months following my diagnosis were tumultuous as I struggled deeply with this new way of thinking about myself and my life. Stories I read from community members with similar issues were reassuring and relatable, however, I felt beaten down by the rest of society as my symptoms were being mocked, imitated, and demonized in the media. These symptoms were stifling and based on clinical and medical descriptions of the mental illness, not on the holistic experience of the individual. Thus, I was apprehensive in telling people about my suffering for fear they would judge me in a different light, based on these misrepresentations. I have never been in such a state of despair and agony as I was at that time. I felt as though I was trapped inside the prison of my mind, and the only escape was to look through my eyes at the outside world where I so desperately wanted to belong. The greatest anxiety came from knowing that I could

never escape, never be outside of myself. My soul, my identity was shredded to pieces and I was left on the ground alone to clean up the mess. I have never had to look so deeply inside of myself to dig up the darkest aspects of my being and bring them to the surface. Clinically speaking, my identity was more concrete, yet simultaneously it became more complicated and complex due to the dominant and negative representations of the mentally ill. The stigma did not disappear, but instead pressed itself more heavily on my heart. Even as an adult, my identity is dynamic and ever-evolving, yet it is smothered by the medical description of my illness.

Now, as a Social Work student it is more difficult to pin down my identity as I have been exposed to an abundance of material, both theoretical and emotionally stimulating. I know this challenge will only be perpetuated when I am in practice, as I will need to be reflective and aware of my own epistemology, especially when it conflicts with that of my clients. Thus, I have felt my self-perception has both been enriched and pulled apart through the course of this semester and I continue to have severe doubts about whether or not I will live a life free from the impact of shame. Perhaps clinical and community practice can somehow be entwined for their common goal of relieving distress, but until then I must attempt to reflect on how stigma has and will continue to shape my identity. However, I am hopeful, as in the field of social work diversity and personal experiences of adversity seem to be celebrated as beneficial tools for practice. This can serve to help me shape a more positive perception of who I am.

Faculty of Social Work (FSW) Equity Forum Reflections

As an MSW student at Wilfrid Laurier University I have been fortunate enough to attend two annual FSW Equity Forums – in 2012 and 2013. Both forums were insightful, inspirational, and emotionally moving, and I felt it was important to reflect on my experiences as an attendee.

2012.

In a word, I would describe the Equity Forum as *inspirational*. It inspired me to shake free from the fear, guilt, and shame related to my experiences with mental health. It encouraged me to tear down the walls of isolation that segregate me from what is deemed as “acceptable” in society.

The panelist discussion was not what I expected it would be. It was far more personal and powerful than I could have envisioned. The courage and passion that was demonstrated by the panelists gave me hope for my own future as a citizen struggling with the label of being “mentally ill”. By sharing their stories in unique and personalized forms, I felt the panelists took back their voices once stolen by oppression. In the process, they were able to continue along the path of healing. They proved that beyond the stereotypes of disability, race, and mental illness lie gifted and resilient beings. Those suffering under the domination of stigma, including myself, often feel the need to hide these painful stories. This forum taught me that we need to speak the truth, *especially* if it is painful. How else are labels to be shattered, if not by revealing the complex and talented human beings that hide beneath?

With their trust and passion for equity steering them, the panelists strived to have any effect on the audience in a moving way. Although I cannot speak on behalf of my colleagues in attendance, I can say with confidence that through this forum I found my own desire to raise awareness of stigma and violence, one shared story at a time. We must allow our “deficiencies” to be recognized as gifts, and our battles with marginalization to be used as stepping stones toward a positive sense of identity. It is time to break the silence.

2013.

Today I attended the WLU Faculty of Social Work Equity Forum. The topic of this year’s forum was “Challenging Stigma and Oppression”. I felt truly inspired to be a part of this forum today as the topic spoke especially close to my heart as I have had to deal with stigma in my own way for most of my life. I was curious and eager to learn of other individuals’ unique experiences of stigma in realms that were common to mine, while also hoping to connect emotionally with the stories being shared. I was not disappointed, and the courage shown by the presenters reinforced my belief that I expressed after last year’s equity forum, that by sharing our stories and disclosing our truths, individuals experiencing oppression can begin to break down the barriers of stigma.

During the performance of one of the presenter’s poems, there was one statement that spoke deeply to my heart. She said, “We are cracked but not broken”. I feel the difficulties I have faced in dealing with mental health issues have indeed cracked me and left me feeling shattered multiple times, but I also believe that I am not and will not ever

be broken. My determination to live my life to its fullest has given me a constant sense of hope for what lies ahead and this has kept me from being beaten down by the stigma surrounding mental “illness”. Many times this hope has been stolen from my grasp, leaving me to feel so wounded that I never expected to recover. To this day, I have always recovered. The cracks grow and multiply everyday that I struggle, but they will never break me. The presenter also said that truth comes from the trials we face and the memories we carry, positive or negative. Although there are some tribulations I wish so desperately to forget, I appreciate what they have taught me and what they have done to shape my wholistic being. My truth lies in the suffering I have endured and hiding this truth will not serve to free me from the pain I have experienced; rather it will perpetuate the stigma and the cultural attitude of shame and disgrace regarding mental health.

Another presentation touched me on a more personal level than any other. She asserted that the whole existence of a person must come before the labels attached to mental health issues. We who have been diagnosed and labelled with a mental “disorder” are no less human than those without. Risking oneself by disclosing a diagnosis and more importantly, sharing the rich and detailed story of one’s experiences, will help to break the silence that keeps stigma from disappearing. Although mental health issues carry the burdens of shame, fear, and pain, they also allow one to dig deep within oneself to uncover hope, strength, and perseverance.

I have been struggling with the fear that surrounds my current vulnerability in completing this project. I appreciate the risk I am taking in allowing others to walk beside me in my pain and suffering, however I also understand that the stigma that clouds the judgements and perspectives of others may at times be too crippling to handle. The

Equity Forum this year inspired me and gave me a new strength to carry forward with my work and take the risk. Not only am I making this sacrifice for myself, but I am hoping to give strength to those still hiding under the blanket of shame. This is no longer a risk I want to take; it is also a risk I *need* to take.

Personal Journal Entries

Throughout the past year (2012 – 2013) I have compiled a collection of personal journey entries that I have kept as a way to document important instances in my battle with OCD. Taking part in this research process and studying in the MSW program has inspired and encouraged me to put into writing the trials and triumphs I have been experiencing while growing into my true identities.

November 2012.

It took some time to reveal my ideas regarding my thesis research to anyone. It was not until I became more comfortable with my colleagues that I was able to take a risk in spite of the shame I felt about my mental disorder “diagnosis”. After a couple months in the MSW program I had developed supportive and nurturing friendships that I feel gave me the strength to allow some colleagues to walk beside me in this journey.

To my surprise, each one of my peers supported and encouraged this journey and commended me on my courage to speak out about my *true* experiences. I told them about my struggles, my diagnosis, and my plan to stand up to stigma face-to-face by making my story public. Although I had doubts and concerns about being judged, their positive responses instilled within me a sense of hope that the sharing of my story would reach others and bring comfort to those battling stigma. Some colleagues even revealed that

they had relatives, friends, or acquaintances that had similar stories to mine. This reassured my belief that my research would have meaning and purpose. Not only can I bring awareness to the individual truths about experiences of mental health and stigma, but I may also inspire others to break free from the shame that ties them to the margins of society.

These interactions were unexpected. In my mind I had developed the idea that my research plans would not be accepted positively - as they were; however, it is important that I recognize the context within which these interactions took place. My colleagues are in the Master of Social Work program and are arguably more accepting of diverse experiences and ideas. I am aware that revealing my story to others outside of this context may still prove to be a battle and will require even more courage and determination on my part.

July 7, 2013.

It is hard to see through the tears. They are making my world cloudy and distorted. I do not know why the pain is so gripping today. I feel paralyzed and as though the anxiety has grabbed a hold of my heart with so much strength that I will never break free.

It has been a while since I have had one of these terrible days that make me feel trapped in a prison of worry and doom. I am sitting on my bedroom floor bawling uncontrollably because I am too stuck in my fears to move. Today I feel like I cannot even get out the door.

The moments like these that seem to stretch out for agonisingly long periods of time make me question why I was made to feel this way. I did not choose to have debilitating anxiety so what have I done to deserve it? It is not fair. I always wonder what it would feel like to not have OCD. Life would be so much easier.

July 28, 2013.

The past few weeks have been a continuous struggle. As soon as I free myself from one obsession another one begins. I have been debating in my mind how much I should reveal in my research. I have made a commitment to be authentic and transparent, but I fear I will share too much. I want my audience to understand how I feel so for now I am going to attempt to put into words the complex workings of my brain and how mangled I feel inside.

When an obsession or worry strikes it feels like I have suddenly hit a wall or been kicked in the stomach. A wave of panic washes over me and my body feels like rubber. It is so difficult to continue with my day that I often sit down, unable to move. When I am at school or work the best I can do is fake it. I put on my mask of capability and strength while I crumble helplessly inside. I have developed quite a talent for imitating stability while internally crawling through the pitch black tunnels that weave through my mind. Sometimes I get so lost in the maze that I completely let go of the obsession and break down. When I cry uncontrollably I feel like I am surrendering my body, heart, and mind to the anxiety. I let it swallow me whole. When I am this helpless and afraid, surrender is simply easier than fighting the never-ending battle with myself.

Today I surrendered. Twice. When I look in the mirror I see a red, puffy reflection of someone I used to know. From the outside my body looks healthy and strong, but inside I feel like my heart is in shreds – the product of a deadly warzone. I pick up the pieces of what is left of the wreckage and desperately hope it will remain intact for another day. I am not sure how or why, but I always seem to have at least a drop of hope. After nearly twenty years of fighting the war, I have somehow managed to carry on. Tonight I have to hope that I will survive to fight another day.

September 9, 2013.

Today was important in my journey of healing and growing in my struggles with mental health. I was meeting with my thesis advisor to discuss my project and my next steps toward completion. In order to get a sense of which themes would possibly present themselves in my data, she asked me to read any passage aloud.

I chose the first piece of writing on the pile of papers I held in my hands. I felt excited and encouraged to be able to share with her something that shed just a small stream of light on my experiences with OCD. As I began reading, I felt self-conscious, not because of the content but of my writing style and ability. This is typical as I am always convinced I will not be quite “good enough” to meet anyone’s standards. Emotionally, however, I was fine.

Then I read the second paragraph which dug more deeply into the trenches of my pain. As I described my childhood experiences of living with an unknown “disease” – the shame, the guilt – I could feel my deepest heartaches creep from chest and grip my throat. As I choked on this flood of pain and held back the tears, I took a breath and apologized

for my behaviour. Even in the safety of a private room with someone I trust, I still felt the need to hide my emotions and remain brave and “stable”. I realized at this moment what was happening.. For the first time in my life I was making my story public. I was hearing the horror, pain, and endless struggle of a child – now a woman – with mental health issues. But it was *my voice* I was hearing! I have shared bits and pieces of my story to my friends, parents, professionals, and some colleagues, but this was different as I was digging so deep into the details of my anguish rather than glossing over it as if everything was just fine.

This was a poignant moment in my life as for the first time I was revealing the genuine and raw hurt with which my life has been drenched. As my voice quavered I was determined to continue. The emotion bubbling up inside of me was one of the inspirations for taking on this project. I have had to suppress this pain and put on a mask of bravery for so many years in fear of being judged unfairly. This project is my chance to break free from the impacts of stigma and share my story without apology. I refuse to be pinned against a wall by fear and shame. I am who I am, and I have OCD. People deserve to hear the truth about my experiences and I deserve to have it be heard. Reading just a fragment of my story aloud in a small office with an audience of one may appear trivial to some, but for me and for others battling with the stigma of mental “illness”, it could prove to make some type of change, and any change is better than none.

From the Shadows

I was pushed to the ground
Not allowed to speak
My voice was silenced
My hands were tied
Stifled by society
I held my story close
For fear it would slip away
Kept my heart to myself
And hung my head in shame
They would not understand
They would tear me apart
And hold up my screaming guilt
Only to shatter my heart
Feared judgement for so long
I became a judge myself
Stepped into the fire, the margins

Where I hopelessly knelt
Hid my face in my hands
While trying to help
But could not reach a soul
Without finding myself
Then a flicker of light
Ignited within
A calling, a mission
A place to begin
Winding down a path
Of enlightenment and pain
While shaping my being
And taking my aim
Oppression will no longer fog my mind
Nor pull me away
Nor render me blind
I will emerge from the shadows

And take back my ground

My voice for once

Will be soaring aloud

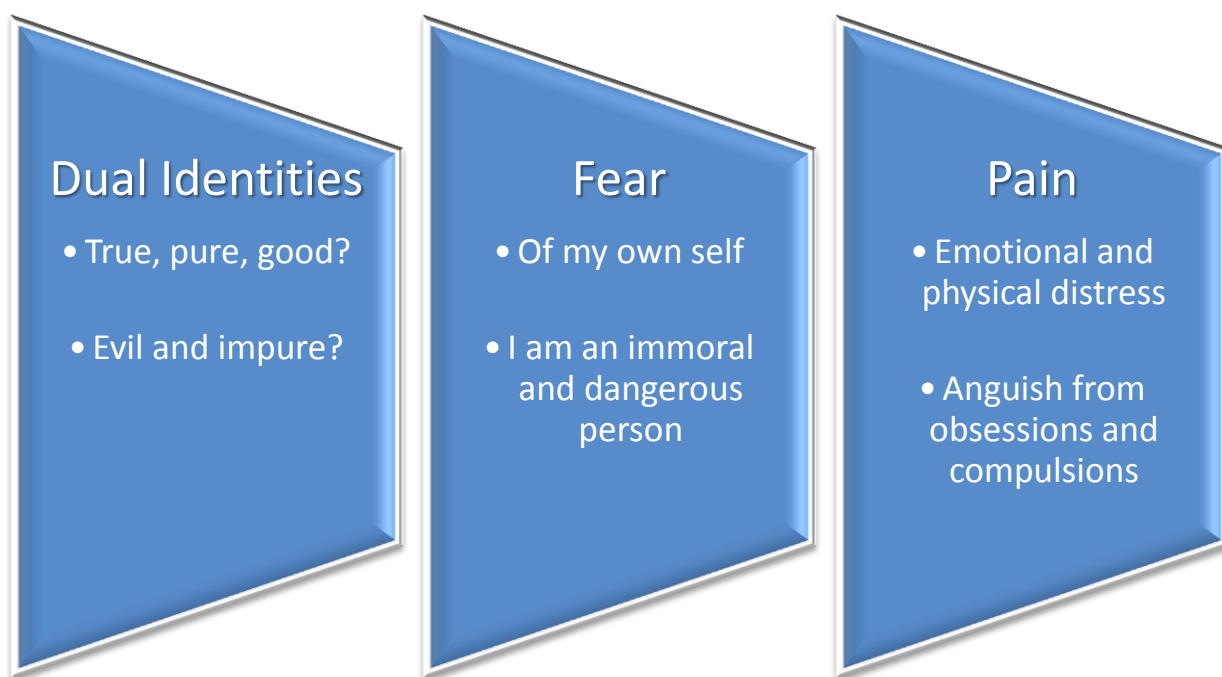
This is a poem that describes my personal journey through oppression, and how I have come to not only accept but celebrate my experiences of adversity. When I began the Master of Social Work program, I was still struggling with my identity, the oppression I felt from society, and the feeling that I did not quite belong within any social contexts. I wanted to use my own experiences to reach out to those suffering desperately in the margins of society, yet felt the need to hide these experiences because they were deemed “unprofessional”. I did not understand how I could truly help those in distress if my own stories were being shoved out of view, so as not to offend anyone who may be watching.

I have wanted to share my stories of suffering silently in the shadows of society for many years in the hopes of giving someone just like myself the courage to expose their true identity with pride. After beginning the MSW program I felt excited because I was in an environment that would finally value my experiences. I felt something spark inside of me that I have not felt for many years: a sense of rejuvenation and hope. I could finally let my own trials be used to enrich the lives of others, while shaking free of my own shame and guilt to reveal my true and ever-evolving identity. I have a newfound passion to emerge from the margins of society and to help others do the same. I have realized that my experiences are truly deserving of respect and I refuse to keep them

tucked away, as they are an integral part of my existence and will most certainly serve to validate the anguish felt by other marginalized individuals.

Chapter 5: Guilt - The Relentless Storm Within

The wrenching pain has been too much to bear. I do not understand how I battled with my own conscience for so many years – completely isolated and trapped within my own mind. Beneath the surface of my exterior lie the complex and somewhat disturbing inner workings of my brain that continue to feel alien to me. Deep within my soul I am an honest, caring human being, yet simultaneously a relentless storm of terrorizing obsession has been brewing within me since I was a child. It tears me apart from the inside out leaving me breathless and screaming in emotional agony. I have learned to tame the storm to a dull roar, however this growth has come at a price – that of guilt, searing pain, and the violent clashing of my two opposing identities.



Guilt has strangled me and torn at my heart since I was a child, even before my OCD “symptoms” came to the surface. It has shifted its shape as I have grown and

developed into an adult, and yet it suffocates me to this very day. It tries to tear me down, to slash my knees and leave me weak and bleeding on the ground. As a way of lifting myself up from the ground and finding a way out of my terrible suffering, I scramble to find how others define guilt. Some say guilt is the belief that one is responsible for a real or sometimes imagined outcome or offense, coupled with an urge to set things right (Lindsay-Hartz, 1984; Tilghman-Osborne, Cole, & Felton, 2012). They tell me that this urge can lead to confession, performing compensatory actions, or the seeking of punishment (Fedewa, Burns, & Gomez, 2005; Lindsay-Hartz, 1984). Guilt becomes inappropriate when it involves rumination and an exaggerated sense of responsibility for outcomes over which one has little control (Tilghman et al., 2012). I have experienced an excessive, dominating, and exhausting guilt that has led me to self-deprecation and desperation nearly every day. As I developed and matured through childhood and adolescence, I constantly believed that my violent thoughts were violating and hurting other people, even though I never made them aware that I had such thoughts. This often motivated internal reparative, compulsive behaviours (Fedewa et al., 2005).

I continue to feel a tremendous amount of guilt, not only for the thoughts that seep into my consciousness, but also for the mistakes that I have made. I constantly question my morals and values and often convince myself that I have done something terrible. This is a battle I face with my own conscience every day, and my need to rationalize any misdemeanors leaves me riddled with guilt and dread. There have been moments when I have felt hopeless, exhausted, and convinced that I must punish myself for my perceived and questionably invented transgressions. Similar to the findings of Baines and Wills (2002), I often feel like I am a moral failure. I have been internally conflicted for my

entire life as I have had to deal with my obsessions and compulsions in isolation for so long. Within my experiences of guilt I have identified three distinct manifestations of it: my dual identities (impure and evil versus good and true), fear of my own mind, and pain.

Dual Identities

The intense guilt that has burdened me is in part due to the clashing of my two identities: my true, pure, and good self and the self which is fueled by my OCD “symptoms” – evil and impure. Prior to developing an understanding of what OCD is and what it can do to one’s mind, I felt that I internally existed as two opposing beings. The battle between what I knew was my true self and the horror that constantly raced through my mind led to an agonizing guilt that can only explained as the ripping in half of my soul. The research of Ferrier and Brewin (2005) suggests that individuals with OCD tend to make negative inferences about the self, believing that the self is comprised of bad and immoral traits. I did begin to question my identity and morality, which led me to feel like a stranger in my own skin. I did not recognize myself, both physically and emotionally, as I fought to keep the war of my identities within my control. *I was often convinced that my internal struggles meant that I was a fundamentally bad person, but deep within my heart I knew I was good.* Each time an obsession surfaced, a voice in my mind screamed:

HOW could you do that!? How could you think that way!? You are bad. BAD.

You are a terrible person.

I felt so consumed by these thoughts and this internal message that they seemed to invade and dissolve all aspects of my existence. I could not make sense of this biting

conflict that was raging inside of me. I felt as though the “evil” OCD half of my being was uncontrollably smothering my true self, leaving me to conclude that there was something wrong with me, that I was morally defective. I would emotionally punish myself, repeating in my mind that:

There is something seriously wrong with you....There is absolutely NO doubt now that you are not good. People like you do not deserve to be happy.

I truly felt like a monster. Was I being possessed from the inside out by some demonic being? Where were these thoughts emerging from if I had a pure heart like I so deeply wanted to believe? I reached desperately for any rational explanation, and yet I could not find one; rather I continued to believe that my horrifying thoughts were born of my very soul and being. People with OCD tend to automatically assume they are evil and guilty for having violent and aggressive obsessions, and I was no exception (Spett & Mollick, 2013; Wilhelm, 2003). *I was convinced by the guilt which rotted my soul that I was truly evil*, and the possibility rattled me to the very core of my being. The prospect of becoming this evil being filled me with a chilling fear which I held close to my heart for so many tormented years.

Fear

I cannot remember a time in my life when I have not been laden with excessive guilt, and my guilt has often taken the form of a fear that I truly was the immoral and dangerous person that I was struggling to fight. Others define fear as an emotion caused by the threat of pain, harm, dread, or a feeling of anxiety concerning the safety of someone (Oxford Dictionaries, 2013). As my OCD “symptoms” began to emerge, my

guilt was interwoven with excessive worry and dread surrounding my own safety, and my belief that self-discipline and “mental punishment” would extinguish my ritualistic and obsessive behaviour. I was burdened with an immense fear that I would lose complete control of my mind and feel compelled to perform violent acts without remorse. I also feared that my inability to perform certain actions correctly would lead to catastrophic consequences.

I was 8 years old when I started to perform these secret actions – what I now understand to be compulsions. I did not know why I felt the need to tap, touch, or look at things in a certain way, or why I believed I would be “cursed” if I did not think a “pure” thought while I performed these compulsions. I was terrified of pictures, mirrors, light switches, television remotes, and stairs. I spent hours walking up and down the stairs, looking in the mirror until it was done “right”, turning things on and off, and walking by photographs without looking at them in a “bad” way. I put certain words in quotation marks because I still do not understand what these words truly mean. I experience these compulsive feelings that are so complex and abstract that I continue to fail to put them into words.

Wrapped around my compulsive acts, or compensatory behaviour, was the nagging feeling of dread that harm would come to me, my family, or even the world at large if I did not perform the acts “correctly”. This overwhelming sense of responsibility to prevent negative outcomes leads to feelings of guilt and depression in individuals with OCD, and results in less resistance to compulsion (Shafran, Watkins, & Charman, 1996). Caught in the so-called catch-22 situation, the more compulsions I performed, the heavier the guilt would weigh on me, and the more intense the compulsions became. Although

such beliefs involved the safety of others, I never dared to share such feelings as they emerged; rather I held them in my own mind where the fear and exaggerated responsibility continued to build and paralyze me – both mentally and physically.

I eventually began to develop a fear of being “cursed” if I did not think “pure” thoughts while completing compulsive acts. I started to develop religious scrupulosity surrounding my compulsions. Others have found that scrupulosity is faced by many people with an OCD “diagnosis”, leading to an exaggerated sense of moral responsibility (Deacon & Nelson, 2008; Nelson, Abramowitz, Whiteside, & Deacon, 2006). The symptoms of scrupulosity related to OCD include unwanted sacrilegious thoughts (usually of the Devil), and overwhelming fear about committing a sin (Nelson et al., 2006). I spent a lot of time ruminating over images of the Devil in my mind, and worrying that It was somehow possessing me to do these strange acts (compulsions) and think the confusing thoughts surrounding them (obsessions). I was convinced that by not repeating the compulsions until they were done “perfectly”, I would risk bringing harm to myself and others. If my thoughts were sacrilege as I was performing these acts, I would have to pay the ultimate price of being damned and cursed forever. The terror that accompanied such images and beliefs was so horrific that it only fed the cycle of obsessions and compulsions that stripped me of my energy and hope of emerging from the darkness.

As I grew older my guilt evolved and centred on rumination about what my compulsions meant in regards to the person I was, and I truly feared this revelation. I spent countless hours trying to rationalize my behaviours. I would put aside sleep and crawl into the depths of my mind to decipher the puzzles that lay within. I teased apart

the cognitive, emotional, and physiological processes that accompanied these compulsions while attempting to diligently rationalize my behaviour. I made such abstract arguments against the nagging voice inside telling me that nothing would be okay because I was “crazy”. As is found in individuals with panic disorder, I feared doing something uncontrolled, and most of all I feared insanity (Beck, Emery, & Greenberg, 2005).

The beast awaits the mind's impure flesh

Forget my life and all it holds

All I ever held in the palm of my mud-drenched hands

I had to wash them clean

This was my method for neutralizing the guilt, the fear, the “beast” named OCD that I tried so desperately to ignore. I feared that my life was collapsing in on itself and that I would never escape the demons that clawed at me when I tried to break free from the prison of my skull. I promised myself that I would go to sleep after I solved the puzzle of one last compulsion or obsession, but the more I persevered, the further into the maze of confusion I wandered. I felt personally responsible for my compulsive acts and thoughts and my lack of will-power to dissolve them. Persons with mental illness tend to develop guilt-related self-associations and self-blame (Rusch, Todd, Bodenhausen, & Corrigan, 2010). I only blamed myself for feeling confused and afraid and I truly believed I deserved to feel this way; as such my rightful “punishment” was to spend as much time and energy as was required to rationalize my behaviour and drive away the

beast. These were, however, fruitless ventures as my heart pounded uncontrollably with panic as dread continued to chase me.

In one such night, I was suddenly ripped from my frightening yet familiar ritualistic behaviour as violent obsessions and images of committing disturbing acts suddenly engulfed me from the depths of hell. I have never felt more terrified in all my life than I did that long, dark night. My existence as I knew it was forever changed, and at that moment I believed any life I had worth living was being stolen from my ever weakening grasp. I truly believed that I was losing control of my mind and I feared that I would inevitably commit the heinous acts if I did not do something to stop the thoughts from spilling into my brain.

The fear and guilt I experienced stemmed from my belief that if I could think these horrid thoughts and conjure up such gruesome images, I was not far from actually committing such acts. I even went so far as to believe that thinking the thoughts made me equally guilty as a murderer or violent criminal. This dysfunctional cognition that a violent thought is equivalent to the act itself is referred to as thought-action fusion, and some individuals with OCD fear that their thoughts will inevitably lead them to commit these acts (Purdon, 2004; Spett & Mollick, 2013). Due to my obsessive thoughts and images, I lived in utter fear of my own mind for many years. I was afraid to be awake, afraid to sleep, afraid to be near anyone or anything. I was absolutely afraid to exist because there was not one part of my reality that was safe – physically, emotionally, mentally, or subconsciously. *Let me out of this prison. Let me out of my mind. LET ME OUT!* But I knew I could never leave. I was stuck,

Working for the terror aching inside

Cracking open

Exposing where the paranoia had to hide

I could no longer deny the paranoia that began to develop in my mind. Not only did the obsessions progressively lacerate my brain more relentlessly as I grew older, but I actually started to believe that I was attempting to hurt people. I did not understand where this irrational (yet at the time seemingly realistic) belief was emerging from. In hindsight I realize that I never hurt anyone, nor would I have ever come close, and yet something inside caused me to believe this was the case. I understand now that these feelings and beliefs evolved internally due to my “diagnosis” as feelings of fear and guilt are common and often displayed in approximately 25% of OCD sufferers (Mortiz, 2008). I was being mentally tortured by my own mind. There were moments that I felt so hopeless in my guilt and so shaken with terror that I did not know if I could live one more day carrying this burden I did not fully understand. It came to a point when my guilt and fear were so intense that I was paralyzed, unable to forgive myself, unable to function.

As a means of reducing my guilt and the fear I held of my own personhood, I began to “confess” my transgressions – the negative thoughts and perceived harmful actions that were oozing from my being. For many years, I could not verbally confess my horrendous secrets because I was too afraid to make my internal battles real to anyone, even myself. I confessed in secret, by writing down every “bad” thought that raced through my mind. I eventually had dozens of scraps of paper scattered throughout my home with illegible words scribbled in every direction. I could not rid myself of the guilt

in my heart because I did not understand *why* I had these thoughts, and I feared the reasons. All I knew was that they were disgusting and unacceptable to me, but writing them down seemed to reduce my own fears if only briefly.

Not only did I fear that I would commit the violent acts that swirled through my mind, but I also began to fear objects surrounding me. I felt as though I was a danger to myself and that the only solution would be to tie my hands behind my back or to sit in isolation, away from any threatening “weapons”. I feared sharp objects the most such as razors and knives. The very sight of them caused me to heave in panic while my mind became flooded with graphically violent images. Driving also filled my heart with dread as I believed I was truly capable of harming myself or others. I kept such fears trapped within my own mind however, as the thought of revealing such ideas caused me to shudder in fear. It often felt as though fear took on a physical state and embedded itself within my blood, coursing through my veins and filling my body with its poison. Although I now believe this feeling was punishment enough for my soul, at the time I thought I deserved much worse and would pour my energy into rationalizing such urges and ideas for as much time as was required to come up with an explanation.

Fear has driven me to the edge of desperation and frustration for far too long. Fueled by my guilt and feelings of dread that my mind was a dangerous weapon, it has taken over my consciousness and fed into my compulsive and obsessive patterns of thinking and behaviour. Consequently, this fear and panic has often led to feelings of immense and agonizing emotional pain which has left me vulnerable to the guilt that strangles me every day.

Pain

Pain can be defined as the emotional state of mental suffering or distress, and I believe my own pain has been the result of the overwhelming guilt and fear that has surrounded my experiences with OCD (Oxford Dictionaries, 2013). The anguish I have felt as a result of the battering obsessive thoughts and the nagging urge to perform compulsions has torn at my heart since my symptoms began to emerge. My thoughts and actions caused intense distress which interfered with my daily functioning because I only blamed myself for being this way (Baines & Wills, 2002). This emotional agony has often manifested itself in physical discomfort, sometimes in the form of a panic attack. I have often experienced heaviness in my heart, tightness in my chest, a sinking feeling in the pit of my stomach, trembling, heaving, sweating, and an aching in my head (Beck et al., 2005). I often describe the mental torture I have experienced metaphorically with images of physical violence and pain, as I feel it is the only way to truly convey my inner turmoil. On the surface one may believe that the compulsive behaviours and false obsessive messages scattered throughout my consciousness would cause little dismay; however the guilt, panic, and fear that accompanies such cognitions has been at times intolerable.

When my mind suddenly became flooded with gruesome images during my adolescence I felt more misery than ever before. I did not choose to have unwanted and violent obsessions and I have never wanted them...

So on my bruised and slashed knees I knelt

And screamed in pain as the blood was drained

Making rivers in the ground

I was pleading for peace

But peace never came because I was soaked in pain. I felt guilty for having these thoughts, these feelings, guilty for being the person I was becoming. It is difficult to explain the sense of suffering, dread, and unforgiving pain that coursed through my body when the obsessions took hold (Bains & Wills, 2002). I so desperately held onto the hope that these feelings would fade away as the days passed, but it was only the beginning of a long, winding journey down the tormenting path of obsessive thinking. I attempted to push away the thoughts whenever they crept into consciousness, but the harder I tried to resist them the stronger they gripped at my mind. *I was suffering. My soul was being shred to pieces and I was left alone on the ground to clean up the wreckage.*

There have been some instances where the mental pain was so overwhelming, flooding over my entire body and mind, that I felt completely lost in hopelessness and desperation. The research of Levi, Horesh, Fischel, Treves, Or, and Apter (2008) reports that although unbearable mental pain by itself does not lead to serious suicide attempts, it is a contributory factor. While lying paralyzed on the floor, I have envisioned myself attempting suicide while convincing myself it was the only escape from the torture and guilt I was feeling. I was unsure if I truly wanted to die or if my OCD was playing havoc on my mind once again, but the pain was incredibly real and nearly too much to endure.

This pain was so relentless and ferocious, gnawing at my heart without mercy. For so many years I had to attempt to fend off this pain alone, within my own mind and

being. I have travelled to the dark depths of my own psyche and often left to wonder if I would ever escape.

My thoughts

Making a maze in the grooves of my brain

That will never be unravelled or explained

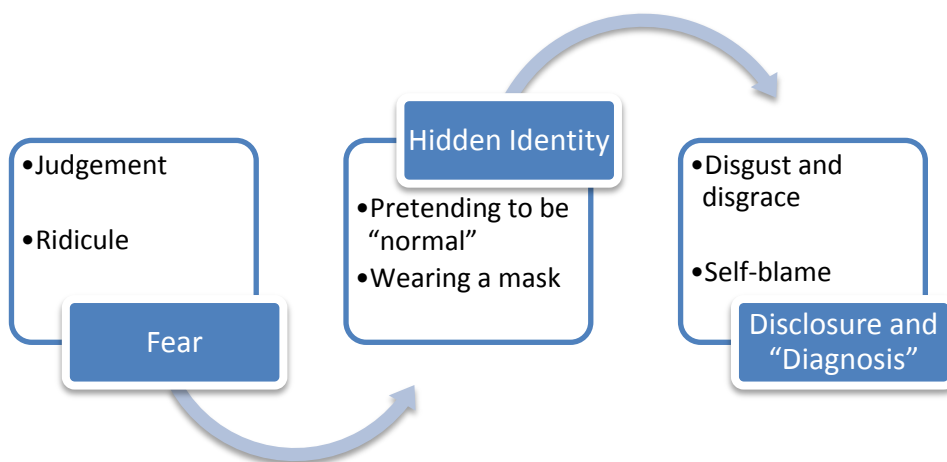
And my heart was still torn completely apart

My bleeding heart

There have been moments when the pain has gripped me too tightly, and all I can do is cry uncontrollably. The thoughts which slash my brain continue to mangle me inside, leaving me feeling lost and broken in despair. I have often wished for physical pain over the intangible emotional fire that burns and cuts so deeply into my soul. It holds me hostage in isolation, alone and afraid. I have felt so guilty for my thoughts that I have been made to believe I am worthy of this internal punishment. Rather than reaching out for external support as a child and adolescent, I continued to suffer alone in the darkness of my own shadow.

Chapter 6: Shame - The Deafening External Roar

The excruciating internal pain and suffering that has relentlessly shred my heart has never been a solely internal suffering. It has always been inseparably twined with and further aggravated by the relentless external storms of society and stigma surrounding mental “illness”. In my darkest hours I have had to not only navigate my own internal discrepancies and clashing identities, but I have also had to consolidate negative societal images with these negative self inferences (Ferrier & Brewin, 2005). The lack of education and understanding surrounding mental health when I was developing into adolescence and adulthood left me to believe in the stigmatizing labels and images of the “violent psychopath”. As such, I felt ashamed of who I was and feared the judgement and ridicule of others. This led me to hide and suppress my “symptoms” and “second identity”.



When I reflect on my experiences with OCD throughout my life I can easily recognize the excessive amount of shame that has bound me to secrecy. Shame is a painful feeling of distress caused by the consciousness of wrong behaviour, leading to

dishonour or disgrace (Oxford Dictionaries, 2013). Shame evokes feelings of inadequacy and embarrassment, leading one to withdraw and hide his or her defective self from others (Fedewa et al., 2005; Lindsay-Hartz, 1984; Pattison, 2000). Hyman and Pedrick (2005) state that people with OCD are typically secretive and shameful of their obsessions and compulsions and consequently disguise their difficulties. Most individuals with OCD wait years, and even decades to seek any help or support for their mental health issues (Hyman & Pedrick, 2005). This research reports that the average time between the development of issues related to OCD and the seeking of treatment is 7.5 years (Hyman & Pedrick, 2005). It is this kind of shame that has weaved its way through my experiences with OCD and prevented me from seeking help and sharing my struggles for fear that I would be judged unfairly by those in my intimate and wider social systems.

Fear

They would tear me apart

And hold up my screaming pain

Only to shatter my heart

Growing up I had an intense fear of what the consequences of self-disclosure would be. I held within my mind an inaccurate and stigmatized image of who I was and what would become of me if I ever let my secret free. Whenever I felt compelled to perform ritualistic behaviours, or was overcome with disturbing thoughts and urges, the image of an asylum flashed before me. I would attempt to discipline my mind by reminding myself that...

... If you do not stop doing this they will take you to an asylum and lock you up.

My mind was flooded with visions of white rooms with small windows in the doors, and my family solemnly staring in at me as if I were an animal at the zoo.

I held an image of animality, of an asylum becoming my cage, and this perception of myself was incredibly frightening and shameful (Foucault, 1965). I most prominently feared this type of confinement. I was not entirely certain what this confinement would look like, but I truly believed it would be my punishment for acting and thinking “abnormally” (Foucault, 1965; Goffman, 1959). The beliefs and images I held about confinement, mental illness, and unreason were somewhat reflective of reports of the Hôpital Général in Paris: a moral institution founded in the mid-seventeenth century that punished and corrected the insane (Foucault, 1965). My beliefs also coincided with images of the eighteenth century cells of Bicêtre, a hospital in Paris converted to a prison and later a lunatic asylum. The dungeons and cells were reserved for the dangerously and violently insane and held only straw beds and leaking walls (Foucault, 1965). I did not read Goffman or Foucault at the time but I feared the powerfully negative images and believed that because I would shame my family if I revealed my secret I deserved to be removed from society and forced into an institution or asylum (Foucault, 1965).

Many individuals suffering from symptoms of OCD are afraid of being ridiculed or locked up in institutions or asylums such as these, and thus do not share their obsessions and compulsions with anyone (Hyman & Pedrick, 2005). I undoubtedly agree with this statement, but why did I believe this was my inevitable fate? My visions and perceptions of what mental health treatment would look like were outdated and informed by societal structures from centuries past. Was current society so misinformed and

unaware of what mental health issues truly entail that these images were being perpetuated into the present? I was so ashamed of my behaviour and in hindsight, I blame my confusion and shame on the stigma that surrounds mental “illness” and the false representations of “insanity” which permeated my social systems. Goffman (1963) refers to stigma as a deeply discrediting attribute. Based on societal structures and images of the mentally “ill”, I was made to believe that my behaviour was worthy of disqualification from full social acceptance. No person desires to be labelled as sick or “disorderly”, nor fear admittance into lunatic asylums, and as a child it was that label and “treatment” that terrorized me for many years. It is absolutely unfair that I suffered in silence while being made to feel this way because of distorted societal views of mental “illness”.

As I developed into adolescence one of the most influential sources of misinformation regarding mental health was public media. The images I was able to conjure up in my imagination were fed most notably by misrepresentations of the mentally “insane” in television shows, news broadcasts, and films. Media portrayals and dramatizations lead the public to overestimate the risk of violence in people with mental health issues (Wolff, Pathare, Craig, & Leff, 1996). The most common image of people with mental health issues depicted in my childhood memories was one of violence and criminality. In my own experiences, despite the “symptoms” that had manifested themselves, any individual in the media with abnormal behaviour was deemed as a violent “psychopath” who deserved to be locked up. Every time an image was presented to me on the television or in the news, I felt a sharp stab of terror rush through my body as I feared that I too was a dangerous criminal. Similar to most individuals with OCD, I was aware that my behaviours and thoughts were inappropriate because they were

different from what was expected of moral human beings, and I was made to believe that my “bizarre” behaviour could be attributed to my utter insanity (Goffman, 1959; Hyman & Pedrick, 2005). I despised being exposed to media that even hinted at mental illness or criminality. Society told me I was not normal (Goffman, 1959). *You are crazy*. As a child and adolescent, my self-concept was distorted and burned before I even got the chance to fully develop.

I'm crazy. I have to be crazy. There is no other explanation! Everybody knows that if you do things that aren't normal then you are insane. I don't want to be insane. If I am insane, does that mean I am going to do bad things? Insane = violence = criminal.

As I continued into adolescence and my violent obsessions took hold of my mind, I believed my worst fear was coming to fruition. The violent thoughts and images racing through my brain were undoubtedly evidence that I was in fact the violent criminal society insisted I was. The stigma surrounding my “abnormal” behaviours was now being validated by these horrifying thoughts. Any amount of courage I had built up over the years of suffering was being mocked, torn apart by the increasingly disturbing and complicated thoughts now plaguing my mind. Not only was I afraid of being punished or “taken away” to the psychiatric ward, but I now felt a sense of shame because the thoughts involved my loved ones. An unforgiving fear pulsed through me whenever these thoughts erupted within me because I was concerned for the safety of others. As such, my shame was multiplied, elevated, and far more oppressive than it had ever been.

This fear was magnified through social interactions as I recall being a part of or overhearing many conversations regarding people with mental health issues. Although these individuals were socially distant from me and perceived by most as “the Other”, I felt an eerie connection to them. I heard about “the ‘schizo’ that pulled a knife on someone”, “the depressed girl who cut herself”, and “the murderer who didn’t take her medication”. These conversations always left me with uneasy feelings of anxiety, dread, and sheer panic. Although I currently understand the cloud of stigma surrounding these misguided perceptions of the mentally “ill”, at the time I was still victim to those negative images of mental “disorder”. I believed in the abhorrence that was being attached to those with mental health issues. The anxiety I felt was driven by the idea that I would inevitably be placed under the same label as the “schizos”, the depressed, and the murderers. I would be labelled as insane.

My heart it shred

And it bled

Oozing and scorching with the fear it held

I feared the consequences of my repulsive and disgusting thoughts being made visible to others, especially my family and friends. I knew *they would not love me at all*. Furthermore, my most debilitating fear of being confined for my evil and animalistic character left me trapped underneath the weight of stigma, hidden beneath my mask of “normalcy” (Foucault, 1965; Goffman, 1959).

Hidden Identity

They would not understand, they would tear me apart. I did not understand my actions, feelings, or thoughts, so why would anyone else? *I hid my face in my hands.* I hid. I hid myself behind a mask. Every day I pretended to be “normal”. For me, “normal” meant thinking and acting in the same way I perceived others to be doing. According to Goffman (1959) human beings are performers, concerned with keeping the impression that they are meeting the standards by which they are being judged and stigmatized. I was a performer as a child, following the “rules” set out by society for fear of being judged for my strange and seemingly inexplicable behaviours.

According to Taylor (2010) the stigmatization experienced by individuals with mental health issues can be categorized as behavioural stigma because one is considered to be deviating from ‘normal’ behaviour. Unlike physical disabilities, however, individuals with OCD can potentially live in secrecy without ever revealing their struggles (Taylor, 2010). I suppressed my pain and my “abnormal” behaviour throughout my childhood years because I felt I was not living up to the standards of normalcy that I witnessed within my social contexts. *I hid my “second identity” from the community.* I pretended to be only the lovable and compassionate person I believed I was deep in my heart – my first and true identity – while concealing other aspects of myself (Goffman, 1959). I felt that if I could bury the other half of my being deep within my soul it might simply disappear.

I entered into adolescence still carrying the burden of my “disorder” on my shoulders without any support. I continued to be unable to reveal my difficulties and thus

the obsessions and compulsive behaviours became even more ingrained in my life (Hyman & Pedrick, 2005). My hope of ever being “normal” seemed to dwindle with every passing day as my struggles and insecurities worsened and became more debilitating. As I became more cognizant of my social location, I felt it was increasingly important to hide my unfavourable “OCD identity”. I have grown up as an arguably privileged individual in most *visible* aspects of my life. I am a white, middle-class, and educated woman and I have had incredibly supportive social networks throughout my experiences. In reflecting on my childhood and adolescence, before I revealed my struggles to anyone, I recognize that my privileges allowed me to feel comforted and protected when I was suffering. Although I am appreciative of and grateful for this safe and supportive environment, my social location was not without its challenges. I believed that there were certain expectations set out for me (or those of privilege), and that revealing my true identity was unacceptable because I would no longer be living up to those expectations. I feared destroying the image others held of me by sharing my “inappropriate” or, in my case, horrifying thoughts. I continued to hide, bound to self-loathing and desperation, for nearly a decade, when finally the shame was too strong to conquer.

Disclosure and “Diagnosis”

It took a decade of hiding and endless torment to bring me to my knees and surrender to the shame and agony. In a sense I was given a choice when I was dealing with mental health issues. I could conceal my difficulties (or perform my compulsions in secrecy), or I could disclose my issues in the hopes of receiving the care I needed. This is a dilemma faced by most individuals with mental health issues (Bos, Kanner, Muris,

Janssen, & Mayer, 2009). Unfortunately I was never educated in mental health and the only information I received about mental “illness” was retrieved from negative images and portrayals in the media and in my social interactions. I learned through this stigmatization that I should be ashamed of my issues and of the very person I had become. I believed I was *a bad, worthless person*, in every essence of my being. I was unsure of what “help” I might possibly receive if I asked for it, but I could not manage the anxiety alone any longer.

Bos et al. (2009) state that the concealment of a mental health issue is related to stressors and psychological challenges, and I believe I experienced these challenges for far too long. When I finally surrendered and gave up the fight of concealment, it was only because I could not handle how heavily the shame was crushing me. *Ten years of brokenness and now I was shattering*. Revealing my secret identity with my mother was the most shameful act I had completed to date. I have never been more disgusted with myself in all of my life. As I sputtered out my most gruesome obsession through the sobs, I felt that dying would be easier and possibly better for the loved ones I might disappoint upon their knowing. Spilling my secret thoughts for the first time *was like being stabbed with a knife in the stomach. At that moment, I think I would rather have been stabbed than reveal such a shameful secret to one of the people I love most in this world*. Although the words would not come, I apologized in my heart for the disgrace I was bringing on my family...

I'm sorry. For all that I have thought and all that I have felt. I am sorry. Mom, I don't want to hurt you. I love you and I am sorry that I am an awful human being. I am a monster inside. I know you can't see it but the violence in my brain is

always there and I don't know how to stop it. I never wanted to be this way and I am so ashamed of my despicable self. I'm sorry. I'm so, so sorry.

I have never in my life felt so vulnerable, so broken, and yet as courageous and strong as I did at that moment. Simultaneously I felt an intense fear that I would never be loved or respected again because of the thoughts that I believed would define my personhood.

Upon this revelation, I did not place the blame on anyone or anything else. I blamed myself: *"I did something bad"*. But I did not do anything. I did not choose to have these thoughts nor did I choose to be plagued with the symptoms of OCD. I did not ask society to cruelly judge me and other individuals with mental "illnesses". I am not to blame for the dark cloud of stigma that hangs over mental health issues, nor did I stop awareness and education on the topic from being present in my life. All I ever did was try to act "normal" in a community that only accepted the dominant idea of what "normalcy" meant; that is to think and act in a way that did not stray from what was deemed socially acceptable.

Angermeyer and Matschinger (2003) discuss the two opposing views of the labelling of mental health issues. From a clinical stance, this labelling or diagnosis of a mental health problem may provide a better understanding of and clarification surrounding the ambiguity and false beliefs regarding the issues (Angermeyer & Matschinger, 2003). Moreover, sociological role theory states that the labelling of a mental health problem as an illness removes the individual's responsibility for their issues (Angermeyer & Matschinger, 2003). Conversely, the labelling approach emphasizes the negative effects of psychiatric labelling, as it triggers in people the

negative and stereotypical image of the mentally ill. This image is unfortunately still popular within the general public, leading to increased stigmatization and discrimination against those with mental health issues (Angermeyer & Matschinger, 2003).

When I was told I had OCD my experiences were in line with both sociological role theory and labelling theory (Angermeyer & Matschinger, 2003). I felt a wave of relief that there was finally a reason, a valid explanation for my behaviour and thoughts. In hindsight, I was naive to believe that with the revelation of my secret would come a sense of relief from both the symptoms and shame I had been experiencing for ten years. I was definitely wrong. Although I did have a substantial amount of fear my disclosure of mental health issues may lead to further stigmatization from my immediate social networks (namely family and friends), I was unaware that my shame would continue to be perpetuated by stigma surrounding OCD and mental “illness”. I was unconsciously blind to the impact this new label would have on me and how it would keep me under the clouds of shame.

Immediately following the revelation of my OCD label in early adulthood, I continued to hide this idea from most of my friends, family, and acquaintances. I shared my new identity with my parents (as they were involved in my counselling experience) and a few friends. My symptoms and my “disorder” were continuously being misrepresented in the media and even within my social networks. I began to notice how often people would say “I’m so OCD about that” when referring to their cleaning habits or diligence in completing schoolwork. I felt embarrassed and ashamed that the agonizing war I fought with myself everyday could be reduced to a catch phrase that was casually being thrown around in conversation. *I was apprehensive in telling people about my*

suffering for fear they would judge me in a different light, based on these misrepresentations. How would anyone understand that I was experiencing such pain and heartache when all they were being fed from society was the image of a “crazy” person washing their hands one thousand times a day? I do not suffer from compulsive hand-washing but I do understand the mental and emotional turmoil these compulsive actions and obsessions can cause beneath the surface. That is the part that is left out in the medical description and stereotyped images of OCD. I believed if I revealed my diagnosis, no one would understand or continue to see me as the competent and *whole* person they assumed I was.

This shame continued to stifle my existence as a person, a whole person with a “diagnosis” of OCD, even into my academic career as an undergraduate psychology student. *I wanted to use my own experiences to reach out to those suffering desperately in the margins of society, yet I felt the need to hide my own experiences because they were deemed “unprofessional”.* Although I was personally feeling more comfortable with my “diagnosis” and learning how to cope with my anxiety, I never dared to discuss my trials and triumphs with OCD in any academic setting. I felt ashamed that I was having so much difficulty with my own mental health while trying to learn how to help others with similar issues. Even within a context of “understanding”, my subjective ideas and stories were not encouraged.

From my experience as a psychology major, most of the emphasis was placed on the medical model and its descriptions of mental disorders. The medical model posits that a mental disorder is a disease or condition that can be explained in terms of genetic defects and biochemical and/or hormonal imbalances that can be treated medically

(Aneshensel, Phelan, & Bierman, 2013). This perspective was ingrained into my brain since my diagnosis, as I was repeatedly told (through lectures, textbooks, and counselling and psychiatry sessions) that my problems were a result of a chemical imbalance in my brain.

In the midst of my anguish I purchased *The OCD Workbook* (Hyman & Pedrick, 2005) in desperate hopes that it would assist me on my road to recovery. I will admit that it helped with some aspects of my suffering by normalizing my thoughts and behaviours; however in analyzing it now I notice how significantly the medical model dominates its contents. One of the chapters explicitly states that I (the OCD sufferer) “have a problem” while explaining and promoting the medical treatments available (Hyman & Pedrick, 2005, p. 15). According to what I read, my brain was simply broken and I just needed the right medicine to make me feel better, just as though another person would take medication for a physical illness (Poole, 2011). There is absolutely no doubt why I would shy away from revealing my diagnosis to anyone in an academic or professional setting. *They would see me as less of a person.*

Coming into the Master of Social Work program shifted my focus away from the medical model toward a more wholistic perspective of the person; however my shame still followed along beside me through this journey. It took some time to reveal my struggles with OCD to anyone in the program as I continued to feel ashamed of my mental “disorder” diagnosis. I still had doubts and concerns about being judged by my colleagues and I feared they would assume I was weak and unable to manage my own anxiety. My own perceptions of what a mental health caregiver should be (strong, stable, confident) impacted the way in which I valued my own experiences. Simultaneously, I

have and will continue to deeply believe in the notion of the wounded healer – that my own suffering could be used to the service of others (Nouwen, 1972). Our wounds as human beings include alienation, isolation, separation, and loneliness, which leave us anxious and yearning for community and unity (Nouwen, 1972). A mental health provider's willingness to accept their own pain as emerging from the human condition can allow the consumer to feel a sense of empathy and understanding rather than judgement and fear (Nouwen, 1972; Regehr, Stalker, Jacobs, and Pelech, 2001).

However, even in my academic atmosphere of acceptance and nurturance of strengths, the dominant view society holds of the mentally "ill" continues to push me away and degrade my experiences while making me question the value of myself as a wounded healer. Even if my colleagues appreciate and embrace my truths about mental health, I am aware that those outside of this academic context (and possibly some within) will continue to judge and discriminate me based on my label.

Shame. It has constantly battered me and pushed me to the ground. I have felt the effects of shame since the beginning of my childhood, and even after nearly two decades of growing, learning, and working through my mental health issues, shame continues to oppose my belief in disclosure and openness surrounding my OCD "diagnosis". It still questions me when I attempt to reveal painful experiences and shed light on *my truth* about stigma. As much as I wish to believe otherwise, I fear shame will always be one of my most dangerous opponents, battling me every step of the way in my journey of facing stigma. I believe the shame I have experienced has been born of society and false beliefs about mental illness, which have led me to fear the judgement of others and hide my true identity for far too long.

Chapter 7: Hope - Taming the Storm, Dulling the Roar

Emotions can be perceived as being neither within nor without the individual, but as a means of aligning the individual with the collective - the psychic with the social (Ahmed, 2004). There is the assumption that emotions are private, belonging exclusively to the individual or that they are born within and move outward toward social space; however emotions rest upon many factors including the social context in which they develop and the needs and strengths of the individual experiencing such emotions (Ahmed, 2004; Ratner, 2000). Ahmed (2004) argues that emotions are formed by cultural processes and reflect such processes. It is also my contention that identities emerge through these emotional processes and separate order from disorder, the normal from the abnormal, and individuals with OCD from the rest of society.

Emotions are about attachments as they connect us to other things or places, and to the world (Ahmed, 2004). They move us and allow us to feel connected to others, while simultaneously holding us in place (Ahmed, 2004). Emotions rest upon how one dwells in the world with others – how one interacts in relation to other selves and objects; as such emotions involve an interconnection of the personal with the social, based on how one responds to objects and others (Ahmed, 2004). Our beings and identities exist within a cultural and social context and are shaped by discourses and practices within such contexts (Ahmed, 2004; Frederickson & Roberts, 1997). As such, my emotional experiences in relation to mental health and stigma have not been born solely from within, but have been created through the interweaving of personal and societal influences. I have developed within a collective culture that has created an image of mental “illness” from which stigma and judgement have emerged and grown, circulating

through social and public discourses, interactions, public media, and practices. Stigma has not been born within my individual being, but is a product of broader societal relations; as such I have internalized this negative image of mental “illness” as a result of my interconnectedness with this cultural context. I began to view myself from an observer’s perspective – as a “sick” person of little worth and in need of reformation (Frederickson & Roberts, 1997). I internalized social values, judgements, and attitudes and integrated them with my own sense of self (Frederickson & Roberts, 1997).

As I have journeyed along the winding path of OCD – with its dark and hopeless valleys and its sparse yet magnificent peaks – I have experienced my emotions as being influenced by the interaction of both internal and external forces. I have witnessed my inner turmoil, fear, pain, and guilt be intensified by my shame and fear of judgement from society; however I have also been gifted with the ability to use my challenging experiences and inner strength, coupled with positive and negative societal influences, to move forward from the brokenness. I have always carried within in me the torch of hope, and the love and support that has enveloped me from external social networks has fueled this hope when the light seemed dim. I have also been motivated by my own demons and societal stigma and prejudice to use my experiences and channel my emotions towards social justice work to connect my struggles with the struggles of others suffering with the terror that comes with a mental “disorder” diagnosis.

I am constantly challenged by the dominant societal division between the helpee and the helper, the wounded and the healer, the consumer and the provider (Carlson, Rapp, & McDiarmind, 2001; Grant & Cadell, 2009; Nouwen, 1972; Regehr, Stalker, Jacobs, and Pelech, 2001). My intentions for advocacy are grounded in compassion;

however I must remain critical of my values as I shift from student to professional and question the power imbalances that may present themselves as I further my career. My determination to help others may bury the seed of empathy from which my goals have been born. Will I become an oppressor as I provide mental health services, working from within the system that has the potential to discriminate and silence in the face of power? (Corrigan, Edwards, Green, Diwan, & Penn, 2001; Corrigan & Watson, 2002; Mann & Himelein, 2004). My belief in the innocence of my passion to heal the wounded will require constant examination and personal reflection.

Menninger (1959) suggested that hope has a significant role in the health and well-being of individuals as it is a source of strength and healing for those suffering with mental health issues (as cited in Cheavens, Feldman, Woodward, & Snyder, 2006). Hope can be defined as the positive expectancy of attaining a goal (Cheavens et al., 2006). Throughout my battles with the “symptoms” of my OCD, I have continued to believe in better days ahead and the prospect of my fractured heart being sown back together with the thread of hope I have been clinging to...

And I hope

My heart

Will be sown back together

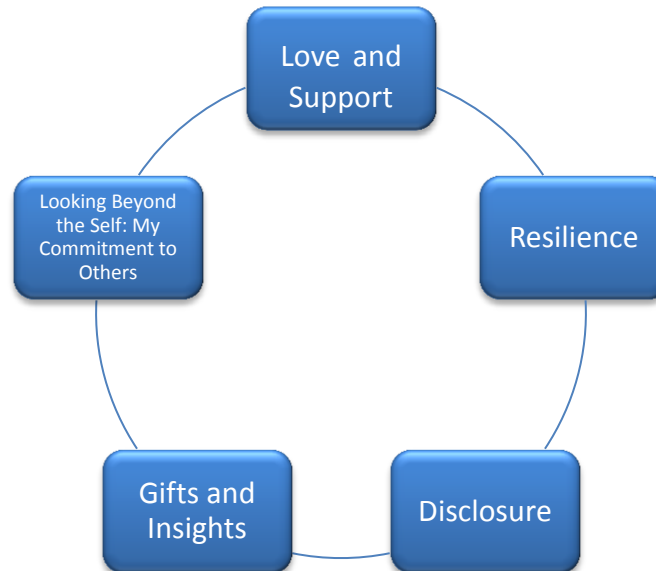
Let it glow and shine forever

In the eternal skies of peace

Put it back together

Let it finally be free

Similar to the participants in the research of Dinos, Stevens, Serfaty, Weich, and King (2004), I feel that my OCD diagnosis has not prevented me from reaching my personal goals; rather I have found strength and motivation to move beyond my limitations. I believe my hope has not been born within or outside of me, but is the result of the interaction between my resilience and the love and support of others. I have come to not only accept my “diagnosis” and the discrimination accompanying it, but I have begun to challenge the power of such prejudice by disclosing my story to others. Through this interaction of internal and external influences, I have felt encouraged to look beyond the self and commit to helping others with the empathy and understanding I have developed.



Love and Support

My anxiety, fear, and pain have at times been unbearable, and too overwhelming to describe. For my ability to carry on I credit not only the love for myself and others I hold within my soul, but the love and hope provided to me by my friends, family, and partner in the depths of my darkness. There were days when I questioned my desire to continue living with such emotional burdens. When I laid on the floor in complete helplessness, the thought of the support that surrounded me brought me to my feet and gave strength to my weak legs. I so desperately wanted to be free from the confusion and violence in my mind and it was through this support from my social networks that I was able to recognize the beauty in my life.

Following my “diagnosis”, I was flooded with a wealth of information regarding OCD. A large portion of the information was based on medical definitions of a mental “disorder”; however I was also able to discover the stories of other mental health consumers. Similar to the findings of Nelson, Lord, and Ochocka (2001), I found this support (although indirect) and that of my family and friends to be the most helpful and inspiring – instilling within me a new sense of hope for happiness and peace. I felt accepted as with the shared understanding of what it meant to live with OCD, I was no longer suffering alone with my challenges. When I was in agony, my parents continued to provide me with an irreplaceable gift – that of compassion, love, and forgiveness. I agree with the research of Nelson et al. (2001) in that it is vital that individuals with mental health issues be embedded within a supportive and accepting community such as this. This support from intimate and wider social systems have maintained the spark of hope

dancing within me while also allowing me to develop into a resilient being in the face of adversity.

Resilience

Resilience can be defined as the notion of bouncing back after being disrupted by change, adversity, stressors, and challenges (Pooley & Cohen, 2010; Richardson & Waite, 2002). A significant feature of resilience is the ability, after some disorder, to access personal gifts and strengths to grow stronger from chaos or disruption (Richardson & Waite, 2002). Pooley and Cohen (2010) suggest that resiliency is the ability to exhibit resourcefulness by using available internal and external resources when faced with conflict. It is a dynamic process of negotiating hardship, which depends not only upon individual factors, but also upon one's interpretations and social affiliations (Wexler, DiFluvio, & Burke, 2009). These definitions more openly allow for differences in meanings of resilience based on cultural and personal contexts. Moreover, they create the opportunity to describe resilience as it relates to individuals or groups whose interpretations or values deviate from dominant societal discourses (Wexler et al., 2009). They also affirm that the related affects and emotions emerge not only from individual resiliency but also from broader communal and societal relations (Ahmed, 2004).

Throughout my childhood and adolescence I have experienced periods of intense desperation and dread without understanding where such feelings were coming from. I oscillated regularly between unbearable anguish and pure joy. Yet, somehow in my darkest moments, I held in my mind the image of a bright and beautiful sun rising each morning regardless of how gloomy and hopeless my situation seemed. I have always

been able to believe that *what is to happen will be right*. I have had to draw on my own strength while demonstrating enough courage to access the external resources available, including professional and personal support.

The findings of Ungar (2008) suggest that resilience is a multidimensional construct which encompasses individuals' ability to seek help (referred to as personal agency) and the availability of such community health resources; it is not simply defined by culturally independent processes. In order to finally advocate for, and navigate the mental health support I needed, I had to rely on my own experiences and relationships to build my resiliency and move forward toward recovery (Ungar, 2008). This was not an effortless feat as I was still reluctant to manage the stigma surrounding mental "illness". I believe the development of my resiliency was hindered at times due to the lack of availability of counselling services and mental health awareness within my community.

As I developed through adolescence and into adulthood, I became more comfortable with my "diagnosis" while learning to cope with my anxiety and appreciate its benefits. *I have come to not only accept but celebrate my experiences of adversity. Beyond the stereotypes surrounding mental "illness" lie gifted, resilient beings.* When I began my undergraduate studies in psychology, I continued to feel ashamed of my "diagnosis" as it was being labelled as a "disorder"; conversely I also realized that I could perceive my experiences with OCD in a more positive light. For the first time I recognized and appreciated the insight I had gained through my struggles with mental "illness" and understood that my experiences had made me a stronger person. I began to feel incredibly grateful to have had such rich experiences that have tested my strength and fueled my resiliency. *I would never have traded my painful experiences for anything.*

My optimism continued to soar as I entered into the Master of Social Work program. When I entered the program *I felt a spark inside of me that I had not felt for many years: a sense of rejuvenation, hope, and resiliency*. I was finally free to deeply reflect upon my experiences with OCD in a more public setting; however this opportunity did not come without heartache. The process of examining my own doubts and insecurities has been challenging and I feel that I have been *winding down a road of enlightenment and pain*. Although I have had to come face-to-face with the guilt and fears that lie within the shadowy depths of my soul, I feel it has been an essential piece of my journey toward healing. As I have progressed through this program I have been given the opportunity to reflect upon my self-perception and identity, while recognizing how this more accepting social context has allowed me to grow in the face of adversity. I have felt more secure, confident, and hopeful about my own selfhood, and this has allowed me to more openly disclose to others my stories of anguish and accomplishment.

Disclosure

The horror of my thoughts and violent urge to end my life was a burden too heavy – cracking me open from the inside out. When I spoke for the first time of my agonizing experiences to my mother and later my father, their grace and acceptance comforted me more than anything else. As was found in the research of Dinos et al. (2004), I felt relief rush over me upon disclosing my experiences and being “diagnosed” with OCD. This allowed me to finally learn some truths about mental “illness”, giving me a fleeting sense of liberation. For the first time in my life I could openly connect with a larger community of those struggling with a mental “disorder”, and this gave me hope for a more peaceful future.

Disclosing my whole and true identity to friends, family, and more distant social acquaintances gave me a new feeling of hope that I would be able to not only survive – but thrive – regardless of the agony that dragged at my heels for so long. When I began the MSW program, I felt I was finally in a place that not only listened to stories of adversity, but respected and appreciated their worth. I began to feel comfortable revealing my complex identity with pride. For the first time I was able to believe that *people deserve to hear the truth about my experiences and I deserve to have it be heard.*

I will emerge from the shadows

And take back my ground

My voice for once

Will be soaring allowed

As I gradually began sharing my story and “diagnosis” of OCD with my fellow colleagues in the MSW program, I was filled with both trepidation and exhilaration. Sharing a personal story for the first time in public can have a transforming effect, and although I was not speaking to a large audience about my experiences, communicating openly about them to individuals in my wider social networks was a personal triumph (Block, 2008). I have continued to struggle with the unrelenting and familiar feelings of shame and embarrassment each time I share my story with another person. I still question my decision to disclose such personal information and feel concerned that I will be perceived as weak and starved for sympathy and attention. This external perception which I have internalized is difficult to fight against, and it only serves to fuel the power

that stigma holds over society; however I feel it is necessary to sacrifice being without this shame in order to tear down stigma and reveal hope.

When I began writing and speaking more publicly in an academic setting about my experiences with OCD, I was wary of how well my ideas would be received. I feared that my intentions would be questioned or mistaken for a selfish attempt at validation. By sharing my narrative and making myself vulnerable, I held within me the hope that I could contribute to the development of such a context. Although writing reflexively about such experiences has been important for my own growth and awareness, the primary goal of my disclosure was to reach out to others and instill within them a sense of hope. I could not help but think that *if I could find the strength and courage to take off my mask and stop pretending to be someone I am not, perhaps I could inspire others to do the same.*

Gifts and Insights

Differences should not be viewed simply as problems to be solved, but rather as sources of vitality, as healing can involve a re-remembering of the past in a more forgiving way (Block, 2008). Block (2008) discusses the McKnight Insights which posit that the focus in community should be one of gifts rather than deficiencies. Social services, medicine, and psychology tend to view individuals with mental disorders as broken - in need of repair, and this labelling can limit their potential (Block, 2008; Poole, 2011). This focus on weaknesses and flaws pushes people into the margins of society, consequently silencing valuable narratives. Rappaport (1993, 1995) has argued for a narrative which challenges the dominant discourse of psychiatry, and states that there can

be an alternative and supportive community narrative which focuses on empowering psychiatric consumers. The dominant perception of individuals with mental health problems is that they are all dangerous and violent. If these individuals were supported in sharing their own narratives of hope, strength, and resilience, the dominant negative perception of mental “illness” could be reconstructed to reflect the more positive aspects of mental health (Rappaport, 1993, 1995).

Throughout my development, I was sheltered from such inspiring stories because society placed the emphasis on deficiencies and stereotypical images of what it meant to have a mental health issue. Rather than celebrating my uniqueness and insightfulness, I internalized the image of a violent and malicious “psycho”. As I have developed into adulthood, I have slowly become more aware of the gifts my “diagnosis” has given me. It has not been an effortless process, as I have had to confront and object the prejudiced dominant discourse of OCD and mental “illness” as a whole. I am now able to recognize the level of internal courage, and sense of hope that was required of me to challenge such beliefs, and the significant insight that was gained as a result. I believe that *sharing my truth will allow others to bear witness to my internal strength.*

Looking Beyond the Self: My Commitment to Others

Then a flicker of light

Ignited within

A calling, a mission

A place to begin

Upon navigating societal and internalized self-stigma, and disclosing my experiences with OCD, I began to believe that I possessed the ability to truly connect and empathize with other individuals diagnosed with a mental “disorder” in particular and with other stigmatized individuals and groups in general. *I realized that my new hope was that others suffering would someday feel the love and support that I was experiencing.* And so was born my passion and mission to help others who are battling against their own demons and the unfounded judgements from society.

My focus is now on celebrating the personal assets of others, rather than placing the emphasis on deficiencies to be corrected. I believe the complexities of the person interact with the “illness” to create something truly unique. Research in the realm of positive psychology explores the areas which are neglected in dominant literature including optimism, gratitude, forgiveness, inspiration, and hope (Gable & Haidt, 2005). These aspects of humanness are vital to the development of strength, and I believe each individual battling with mental “illness” has the potential to use such gifts to become healed and capable of fulfilling personal dreams. The stigma and negative beliefs surrounding mental health serve only as barriers to this hope. In my early adult life, I have continued to learn how to break through these barriers and use my gifts to serve myself and others in the war against stigma.

‘Sanism’ is a term which refers to the oppression, negative stereotyping, and argument that individuals with mental health issues are not suitable to study and practice social work (Poole, Jivraj, Arslanian, Bellows, Chiasson, Hakimy, Pasini, & Reid, 2012). The research of Poole et al. (2012) questions which voices have been silenced and excluded in social work education as the medical model, labelling, and pathologizing are

at the foundation of its teachings. It has even been suggested that social work students with mental health issues are incompetent and unsuitable for the profession and should not be allowed to graduate, thus protecting the field from Mad practitioners (Poole et al., 2012; Royse, 2000; Watkinson & Chambers, 2008).

Although as a “Mad” individual I have had to work through many difficult experiences, I refuse to be defeated by them; rather I believe I can use my experiences to connect with other mental health consumers. The community-based research of Poole et al. (2012) proposes to destroy the barrier that divides the researcher and the researched. As a psychology, and now a social work student, I have continuously reflected on how my own experiences would affect my future practice – by breaking the barrier between the mental health consumer and provider. I have held within me a feeling of excitement that I could use my resilience as a means of connecting with clients in a more meaningful and empathic manner. Grant and Cadell (2009) suggest that prosumers (which refers to an individual who has both received and provided mental health services) can add many benefits to the field while encouraging the celebration of strengths. Research suggests that mental health prosumers have various beneficial gifts and attributes to bring to their work (Carlson, Rapp, and McDiarmind, 2001; Grant & Cadell, 2009). Prosumers can engage with clients in a number of ways by being empathic, instilling hope for healing, and acting as role models and advocates (Carlson et al., 2001; Davidson, Chinman, Sells, & Rowe, 2006; Grant & Cadell, 2009; Stromwall, 2002). Moreover, prosumers can serve as role models for their colleagues through the demonstration of valuing and empathizing with clients’ experiences (Stromwall, 2002). If the social work profession does not openly accept consumer-providers, then it will lose out on the opportunity to add strength

and diversity to the field (Stromwall, 2002). My hope lies in the passion I feel to provide the sort of empathic support for others which was not provided to me until I endured a great amount of inner anguish.

Experiences are neither confined to the individual nor constructed only within the self, but are also intertwined with public systems, practices, and discourses (Ahmed, 2004; Rose, 1996). The shame I have battled through when I felt I had committed an infraction depended not only on my own guilt and pain but also on my belief that others would be critical of my thoughts and behaviour (Ahmed, 2004; Ratner, 2000). Moreover, the lack of available mental health resources, education, and awareness, left my voice silenced and my personal agency constrained. I felt ashamed and fearful of reaching out for support and disclosing the mangled truths that were clawing at me. My own self-identity has been infused with schemas of mental “illness” based on negative societal discourses, structures, and practices (Bottrell, 2009; Rose, 1996).

The findings of Wexler et al. (2009) suggests that future research should explore the ways in which individuals embedded within marginalized groups interpret and respond to prejudice and discrimination. It posits that how these individuals are situated as actors in society depends on these interpretive constructions and reconstructions (Wexler et al., 2009). I have chosen to use my own agency and strength to adapt to current societal structures in order to access the care I have required; however I have recently began to challenge such discourses through self-disclosure and by intending to practice as a mental health prosumer with empathy and passion (Grant & Cadell, 2009). I have made the personal choice to no longer be ridiculed and silenced by stigma, but

rather to use my painful experiences to reach my goals and inspire others to emerge from the margins of society with pride and self-respect.

As I reflect upon my experiences I am grateful for the hope I have been able to cling to throughout my life. Although I have suffered through inexplicable mental and emotional agony, I would not wish for those trials to be taken from my memory as they have allowed me to gain arguably privileged knowledge and insight of mental “illness” and the stigma surrounding it. I have collected such irreplaceable gratitude, hope, strength, and understanding which I will carry with me and share with others for the rest of my life.

“They can’t take it from me, if they tried

I lived through those early days

So many times I had to change the pain to laughter

Just to keep from getting crazed” (McCartney, 2013).

Chapter 8: Looking Ahead

This study seeks to uncover the deeply devastating, excruciating, and powerful emotional processes which accompany mental health issues. It allows my subjective realities and truths to shine through the dominant construct of mental “illness” which tends to blanket societal perceptions and perpetuate hurtful stigmatization (Ritter & Lampkin, 2012; Simmie & Nunes, 2001). It addresses the concerning lack of research literature which digs into the personal stories and experiences of those suffering with mental health issues and public and self-stigma - all of which cause significant social and emotional distress (Chamberlin, 2005; Corrigan & Watson, 2002; Fennell & Liberato, 2007; Simonds & Elliott, 2001; Simmie & Nunes, 2001). I hope to create an opportunity for more open discussion in the field of social work around the challenging of the dominant discourse of mental health while allowing the power of personal accounts to be acknowledged and accepted as truth.

OCD and other mental “disorders” are typically described in a rigid manner based on the classification criteria of the DSM (Ramnsay, 2001; Ritter & Lampkin, 2012). In reference to OCD, the DSM decisively distinguishes between obsessions and compulsions, and often the most common symptoms such as hand-washing and a fear of germs are publicized and stereotyped in society (Hyman & Pedrick, 2005; Ramnsay et al., 2001). My own horrifying experiences with the “disorder” go so far beyond such labels and categories – the anguish, suffering, and terrorizing emotional and cognitive processes could never be completely understood by someone who has not shared such experiences. I have attempted to crack through the surface and into the depths of my mangled being to allow others a glimpse of the true agony of living with OCD. Although

the truth is at times disturbing and difficult to comprehend, its revelation is a vital component in the mission to increase understanding and demolish stigma. Moreover, by illuminating the pain that is caused by societal stigma and discrimination, others may begin to realize just how devastating its consequences can be.

The uncensored stories of mental health consumers may also have implications for treatment as the complexity of the symptoms requires individualized and thorough intervention. OCD cannot be approached with a “one size fits all” belief as each person experiences the “disorder” differently. I have yet to find one account or description of the “illness” that perfectly matches my own struggles. As personal narratives become more openly accepted and discussed in the public domain, the more likely it will be that individuals with OCD will find others to which they can relate; this will diminish feelings of isolation and alienation within one’s own community. The unveiling of more mental health narratives may lead others with similar issues to feel encouraged and ready to reveal their own truths and seek the help and healing they deserve (Brooks, 2011; Goffman, 1963; Hyman & Pedrick, 2005; Ramnsay et al., 2001). Furthermore, mental health providers may benefit from having access to such personal accounts as a means of better understanding their clients while providing empathic and compassionate support from a strengths-based perspective (Block, 2008).

I believe that the voice of individuals with mental health issues has an important place in social work policy, programming, and advocacy (Lammer & Happell, 2003). Lammer and Happell (2003) argue that although consumer participation is reflected in some policy, it is not always being implemented in practice. Mental health consumers have the understanding, insight, and experience to significantly contribute to the creation

and structure of mental health services including the planning, development, delivery, and evaluation of programs (Lammer & Happell, 2003). It has also been argued that although consumer experiences are all unique, their involvement could serve to educate and influence the attitudes of professional service providers to acknowledge and accept consumers' narratives and beliefs (Lammer & Happell, 2003). I agree that consumers and providers should work together to create meaningful policies and programs for mental health advocacy, awareness, and treatment (Lammer & Happell, 2003). A starting point for consumer participation is an open dialogue about their painful, tumultuous, and courageous experiences of living with a mental "disorder" and the stigma that surrounds them. I hope that my research will contribute to this movement toward cooperation between all stakeholders (including consumers) within the mental health service system.

An important and arguably unique facet of my research is embedded within my social location. Through my chosen methodology I have not only placed myself as both the researcher and the researched, but I am also a mental health consumer *and* provider, or "prosumer" (Chang, 2008; Grant & Cadell, 2009). I believe my position is laced with incredible responsibility, and yet it has arguably allowed my story to be expressed through a more critical and reflective lens. The sharing of my perspective and experiences as being both an "insider" and an "outsider" can potentially contribute to the shattering of the consumer-provider binary (Poole et al., 2012). Viewing oneself as separate from others creates boundaries, protecting the inner person from threats or danger from without; however through relationality, one can grow in and toward relationships (Jordan, 1997). As such, I believe this binary of self and other (consumer and provider) has the potential to prevent people from empathic, compassionate, and

meaningful connection to others. Through the nurturance and acceptance of diverse identities and experiences within the mental health field, the profession could be enriched with the skills of empathic, insightful, and passionate prosumers. The therapeutic rapport between consumer and therapist can be enhanced when each person brings themselves into the relationship more fully and clearly; thus the rich experiences and empathy of prosumers have the potential to strengthen the connection (Jordan, 1997). The acceptance and celebration of prosumers' contributions and insights can only be achieved when they are given a platform to share their stories in a supportive public forum. One of the purposes of this study is to contribute to an increase in understanding of how one's experiences with mental health can enhance one's passion for therapeutic interventions, advocacy and justice.

I intend to use my unique position as a prosumer to engage others with my story both within and outside of the social work profession. I believe mental health education within the school system would partially address stigma at its root, as the silence surrounding the topic contributes to fear and misjudgements that lead to discrimination. The research of Pinfold, Toulmin, Thornicroft, Huxley, Farmer, and Graham (2003) found that educational workshops can produce positive changes in attitudes toward people with mental health issues. I agree that the implementation of such workshops would be beneficial, and I hope that my research and personal narrative illuminates the need for more discussion surrounding mental health in order to enhance understanding in children and adolescents. The discussion of such personal stories may also contribute to an increase in youth's disclosure of difficulties and self-advocacy for seeking treatment and support.

Privilege gives me the power to address marginality in a number of ways as it can provide opportunities for me to speak to and educate others about my experiences and mental health in schools, through media, and in other public forums. I hope to speak openly about my hardships and triumphs to social workers, colleagues, students, and the general public in order to build awareness surrounding the issue of mental health and stigma. I hope to not only educate others about mental health – beyond what can be found in a diagnostic manual or positivist research literature – but to also inspire others to challenge the barriers of stigma and oppression and speak openly with pride about their experiences. The more people bring their stories out from the desolate margins of society, the more united we can be in our mission to end stigma and promote awareness and equity.

There are limitations to this study which should be considered and addressed in future research. The findings may not be widely generalizeable due to the chosen methodology, which allows for a single research subject; as such my experiences and analyses may not reflect larger cultural processes (Ellis & Bochner, 2000). Moreover, the deeply personal and intimate nature of the data may be questioned for its authenticity and genuineness (Ellis & Bochner, 2000; Lapan et al., 2012). I do believe however, that this study provides an important foundation for further research in the area of mental health, OCD, and stigma, as it uncovers experiences and realities that should not be ignored. My own findings should fuel the exploration of others' personal mental health and stigma narratives so that more voices can be freed from the chains of shame and discrimination. Future qualitative research within the interpretivist paradigm would allow such stories to be shared in an academic and public forum, which would promote mental health

advocacy, awareness, and social justice. It is time for acceptance, nurturance and love. It is time to talk about mental health. I believe in my voice and the voice of others with mental health issues. I believe in a world without stigma. Do you?

But I'll still believe - though there's cracks you'll see

When I'm on my knees I'll still believe

And when I've hit the ground, neither lost nor found,

If you'll believe in me I'll still believe...

...Because I know my weakness, know my voice

And I'll believe in grace and choice

(Dwane, Lovett, Mumford, Marshall, & 2012).

Appendix A

Table 1

Data log (Chang, 2008)

<i>Data Collection Strategy (primary labeling)</i>					<i>Data Content (secondary labeling)</i>			
<i>Data Set #</i>	<i>Date</i>	<i>Collector</i>	<i>Type</i>	<i>Location</i>	<i>Time</i>	<i>People Involved</i>	<i>Source</i>	<i>Place</i>
1	01-01-03	Harrington	ext: "The Sadness"	home	2003	self	self	home
2	14-09-13	Harrington	P/M: "Revealing My Secret"	home	2004	self, mother	self	home
3	02-10-13	Harrington	P/M: "I Have OCD?"	home	2005	mom, self, counsellor	self	counselling
4	05-01-06	Harrington	ext: "Journey of the Heart"	school	2006	self	self	N/A
5	02-10-13	Harrington	P/M: "The Waiting Room"	home	2007	self, counsellor	self	counselling
6	14-09-13	Harrington	S/O, P/M: "Obsession"	home	ongoing	self, family	self	home
7	05-10-13	Harrington	S/R, P/M: "Do You Know?"	home	ongoing	self, society	self	home
8	04-10-12	Harrington	ext: "Shifting Epistemologies"	school	~1995-present	self, society, colleagues	self	society
9	15-11-12	Harrington	ext: "Shifting Identities"	school	~1995-present	self, society	self	society
10	03-10-12	Harrington	ext: "Equity Forum"	school	2012	self, society, presenters	self	society
11	29-09-13	Harrington	ext: "Equity Forum"	school	2013	self, society, presenters	self	society
12	01-11-12	Harrington	S/R, S/O: Journal	home	2012	self, colleagues	self	school
13	07-07-13	Harrington	S/R: Journal	home	2013	self	self	home
14	28-07-13	Harrington	S/R: Journal	home	2013	self	self	home
15	09-09-13	Harrington	S/O: Journal	home	2013	self, thesis advisor	self	school
16	10-09-13	Harrington	S/O: Journal	home	2013	self, practicum supervisor	self	practicum
17	21-11-12	Harrington	ext: "From the Shadows"	school	2012	self, society	self	society
18	N/A	Harrington	ext: OCD Workbook entries	home	2005	self, family, partner	Hyman & Pedrick/self	society

Notes: S/R = self-reflective, S/O = self-observational, P/M = personal memory, ext = external
 Date = date the piece was written

Appendix B
Informed Consent Form for principal investigator (Katelyn Harrington)

WILFRID LAURIER UNIVERSITY

INFORMED CONSENT STATEMENT

*Emerging From the Wreckage: The Exploration of Mental Health, Stigma, and My
 Experiences of Living with Obsessive-Compulsive “Disorder”*

Katelyn Harrington (principal investigator) and Martha Kuwee Kumsa (advisor)

REB approval #: 3713

As part of an autoethnographic study of OCD, I am volunteering to participate in research for a Master of Social Work thesis. The purpose of the study is to explore how an individual diagnosed with Obsessive-Compulsive Disorder (OCD) experiences stigma.

INFORMATION

Textual data will be collected from the principal investigator regarding her personal experiences with OCD and stigma. The principal investigator will interpret and critically analyze the data to investigate how an individual with OCD experiences stigma, both interpersonally and in relation to community resources. The methodology that will be used for this study is Autoethnography, a self-reflective writing that explores the researcher’s personal experience and connects the story to a broader cultural and social understanding. Participant involvement comes in the form of being included in the researcher’s story based on the researcher’s personal memory and interaction.

RISKS

Due to the disclosure of the researcher’s identity, participant identity within the context of the story may become apparent. Risks include emotional distress, disruption in family dynamics, and loss of privacy or reputation. There may be some regret or emotional distress resulting from disclosure or reflection on the experience of living with OCD.

BENEFITS

The benefits of this research could include validating the feelings and experiences of others with mental disorders, raising awareness and consciousness about how stigma is experienced, contributing to research literature of OCD and stigma, and guidance for future support for individuals with a mental disorder. Moreover, the researcher/participants may gain personal and research insights from the research project.

CONFIDENTIALITY

Aside from the researcher, no names will be disclosed in the data or final report. All data will be saved on password protected files accessible only by the researcher.

CONTACT

This project has been reviewed and approved by the University Research Ethics Board (REB approval #3713). If I feel I have not been treated according to the descriptions in this form, or my rights as a participant in research have been violated during the course of this project, I may contact Dr. Robert Basso, Chair, University Research Ethics Board, Wilfrid Laurier University, (519) 884-1970, extension 5225 or rbasso@wlu.ca.

PARTICIPATION

My participation in this study is voluntary; I may decline to participate without penalty. If I decide to participate, I may withdraw from the study at any time without penalty and without loss of benefits to which I am otherwise entitled. If I withdraw from the study, every attempt will be made to remove my data from the study, and have it destroyed. I have the right to omit any question(s)/procedure(s) I choose. Please note that quotations from the participants' personal reflections may be included, but any personally identifying information will be disguised. I may choose at any time to participate in the study without the use of my quotations in the final report.

FEEDBACK AND PUBLICATION

The results of the study will be used as a part of Master's of Social Work thesis. This work will be distributed to the researcher's advisor and committee member and this work may be presented at conferences and/or published in academic research outlets.

CONSENT

I have read and understand the above information. I have received a copy of this form. I agree to participate in this study.

Participant's signature_____ Date _____

Investigator's signature_____ Date _____

Appendix C
Informed Consent Form for participants

WILFRID LAURIER UNIVERSITY
INFORMED CONSENT STATEMENT

*Emerging From the Wreckage: The Exploration of Mental Health, Stigma, and My
Experiences of Living with Obsessive-Compulsive “Disorder”*

Katelyn Harrington (principal investigator) and Martha Kuwee Kumsa (advisor)

REB approval #: 3713

You may be implicated as a participant in an Autoethnographic research study being completed by a Master of Social Work student. The purpose of the study is to explore how an individual diagnosed with Obsessive-Compulsive Disorder (OCD) experiences stigma.

INFORMATION

Textual data will be collected from the principal investigator regarding her personal experiences with OCD and stigma. The principal investigator will interpret and critically analyze the data to investigate how an individual with OCD experiences stigma, both interpersonally and in relation to community resources. The methodology that will be used for this study is Autoethnography, a self-reflective writing that explores the researcher’s personal experience and connects the story to a broader cultural and social understanding. Participant involvement comes in the form of being included in the researcher’s story based on the researcher’s personal memory and interaction.

RISKS

Due to the disclosure of the researcher’s identity, participant identity within the context of the story may become apparent. Risks include emotional distress, disruption in family dynamics, and loss of privacy or reputation.

BENEFITS

The benefits of this research could include validating the feelings and experiences of others with mental disorders, raising awareness and consciousness about how stigma is experienced, contributing to research literature of OCD and stigma, and guidance for future support for individuals with a mental disorder. Moreover, the researcher/participants may gain personal and research insights from the research project.

CONFIDENTIALITY

Aside from the researcher, no names will be disclosed in the data or final report. All data will be saved on password protected files accessible only by the researcher.

CONTACT

If you have questions at any time about the study or the procedures, (or you experience adverse effects as a result of participating in this study,*) you may contact the researcher, Katelyn Harrington, at harr3970@mylaurier.ca, and 519-998-1860. This project has been reviewed and approved by the University Research Ethics Board (REB approval #3713). If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Dr. Robert Basso, Chair, University Research Ethics Board, Wilfrid Laurier University, (519) 884-1970, extension 5225 or rbasso@wlu.ca.

PARTICIPATION

Your participation in this study is voluntary; you may decline to participate without penalty. If you decide to participate, you may withdraw from the study at any time without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw from the study, every attempt will be made to remove your data from the study, and have it destroyed. You have the right to omit any question(s)/procedure(s) you choose. Please note that quotations from the participants' personal reflections may be included, but any personally identifying information will be disguised. You may choose at any time to participate in the study without the use of your quotations in the final report.

FEEDBACK AND PUBLICATION

The results of the study will be used as a part of Master's of Social Work thesis. This work will be distributed to the researcher's advisor and committee member and this work may be presented at conferences and/or published in academic research outlets.

CONSENT

I have read and understand the above information. I have received a copy of this form. I agree to participate in this study.

Participant's signature_____ Date _____

Investigator's signature_____ Date _____

Appendix D
Statement regarding research interests for prospective participants

WILFRID LAURIER UNIVERSITY

STATEMENT OF PARTICIPATION

*Emerging From the Wreckage: The Exploration of Mental Health, Stigma, and My
 Experiences of Living with Obsessive-Compulsive “Disorder”*

Katelyn Harrington (principal investigator) and Martha Kuwee Kumsa (advisor)

REB approval #: 3713

You may be implicated as a participant in an Autoethnographic research study being completed by a Master of Social Work student. The purpose of the study is to explore how an individual diagnosed with Obsessive-Compulsive Disorder (OCD) experiences stigma.

The research interests of the principal investigator are to explore how an individual diagnosed with Obsessive-Compulsive Disorder experiences inter- and intra-personal stigma within her community. It will use an autoethnographic methodology and its purpose is to give voice to the subjective experiences and interpretations of how stigma impacts the life of an individual diagnosed with a mental disorder. The findings may provide guidance for future research, understanding, and support for those with a mental disorder, as well as raise consciousness about the stigmatization and discrimination of these individuals.

You could potentially be involved in this study as a participant through publicly accessible or private social interactions with the principal investigator. You have the right to privacy and your identity will be protected using pseudonyms, or will remain completely unnamed. You may choose at any time to withdrawal from participation in any conversation with the principal investigator.

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